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# Hope At The End Of Life Among U.s. Military Veterans

Jaime L. Huffman  
*Wayne State University,*

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**HOPE AT THE END OF LIFE AMONG U.S. MILITARY VETERANS**

by

**JAIME L. HUFFMAN**

**DISSERTATION**

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

**DOCTOR OF PHILOSOPHY**

2013

MAJOR: NURSING

Approved by:

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Advisor

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Date

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## DEDICATION

I dedicate this dissertation and the completion of doctoral education to my family. Without their love, support and continuous encouragement none of my achievements would have been possible. I am forever grateful to my husband who juggled work and childcare responsibilities so that I could attend classes. I am thankful to my children, one of whom was born in the middle of my studies, for their endless patience as I asked them for “just a few more minutes” to finish writing. All that I have done in the past seven years of doctorate studies has been for them. They are my hopes.

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## PREFACE

*Hope is a good thing, maybe the best of things,*

*and no good thing ever dies.*

*The Shawshank Redemption*

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## CHAPTER 1 INTRODUCTION

Hope is an essential element of human life. Hope helps individuals cope with chronic illnesses, overcome extraordinary odds and survive in unimaginable conditions. Victor Frankl, the renowned Austrian psychiatrist, who spent more than three years as a prisoner in a concentration camp during World War II, wrote about the importance of hope to the human psyche. Frankl (1984) contended, “Those who know how close the connection is between the state of mind of a man – his courage and hope, or lack of them – and the state of immunity of his body, will understand that the sudden loss of hope and courage can have a deadly effect” (p. 94).

Hope becomes especially important at the end of life. As people enter the terminal phase of life, they have different types of needs. These needs are most often categorized as biological, social, spiritual and psychological (Ferrell & Coyle, 2006). The most frequently discussed concept within psychological needs is hope. By addressing hope other biological, social, and psychological needs of dying persons can be affected.

The construct of hope is considered to be a *universal lived experience* (Parse, 1999), meaning that every person has the potential to have lived the experience of hope. Recently research has been conducted examining hope among various cultural groups and their experiences of the construct (Condiff, 2009; Mok et al., 2010). These studies showed that although hope is universal, different cultural groups ascribe different meaning to the construct. These cultural variations are important for nurses to consider when caring for patients.

Madeline Leininger was a prominent nurse researcher, who produced a theory based on her work with various cultural groups. This theory, which centers on cultural diversity and cultural competence, has informed the way nurses care for patients in all developmental stages of life. Leininger (2004) defined culture as “learned, shared and transmitted values, beliefs, norms and ways of life of a specific individual or group that guides their thinking, decisions, actions and patterned ways of living” (p. 95). Leininger contended that cultural groups include racial and ethnic groups as well as cultures that are socially

constructed. One such socially constructed group is U.S. military Veterans (Rabb & Ban, 2010). In this dissertation I use the Department of Veteran Affairs consistent capitalization of *Veteran* rather than the grammatically correct lowercase *veteran*. This is done to be consistent with the recommendations from the VA.

Research conducted among U.S. military Veterans has shown that as a cultural group, Veterans have different needs throughout their lives than do their non-veteran peers. These needs are related to several factors. U.S. military Veterans, particularly those who served in combat forward areas, have higher than average rates of mental illness and physical injuries. The mental illnesses that Veterans experience most frequently and at higher-than-average rates are depression and post-traumatic stress disorder (PTSD) (Banerjea, Pogach, Smelson, & Sambamoorthi, 2009; Drapalski, Milford, Goldberg, Brown & Dixon, 2008). These mental illnesses can lead to suicidal ideation which can be manifested in suicide attempts and deaths (Kaplan, McFarland & Huguet, 2009; Zivin et al., 2007). The physical ailments that U.S. military Veterans suffer from are often related to combat injuries and it has been reported in some of the literature that they can have higher than average rates of traumatic brain injuries, amputations, and poorer general physical health (Saadat et al., 2010; Wallace et al., 2010).

The construct of hope has begun to be studied among U.S. military Veterans. The only literature that could be found concerning hope among Veterans was in relationship to those who had mental illnesses and those who had made suicide attempts (Cancro, 2008; Lysaker et al., 2008). Findings in these studies suggest that the mental illnesses Veterans experience can be related to a lack of hope. However, no literature could be found which examined the construct of hope among Veterans at the end of life.

Some research studies have shown Veterans to have different end-of-life preferences when compared to their non-veteran peers. A small amount of research exists related to these preferences (Duffy, Ronis, Fowler, Schim, & Jackson, 2006; Fischer, et al, 2007; Freeman & Berger, 2009; Rodriguez & Young, 2006). No studies were found to understand how Veterans perceive their lived experiences at the end of life. The voices of members of this cultural group, which has been shown to have differences in the way they experience end of life, have yet to be fully heard.

**Purpose Statement**

The purpose of this study was to discover the meaning of hope at the end of life among U.S. military Veterans. The information gained from this study adds to nursing's knowledge about the construct of hope and the unique and common perspectives of Veterans. Furthermore, it has the potential to help nurses who are caring for Veterans who are at the end of their lives.

**Problem**

The current body of knowledge related to end of life is extensive. In the past five years nursing authors have published over 6,000 articles on this topic. The three most common themes in the end-of-life research are cultural considerations, pain and symptom management, and quality of life. Populations such as African American and Asian American have been given a great deal of attention in the end-of-life literature in relationship to healthcare disparities (Campbell, Williams & Orr, 2010; Ngo-Metzger, Phillips & McCarthy, 2008; Wells, 2011). Yet, the idea that culture goes beyond ethnic and racial groups is just starting to enter the end-of-life literature. Research with socially-constructed cultures or subcultures such as gay men, lesbians, U.S. military Veterans, and other groups during times of wellness are emerging in the literature (Freeman & Berger, 2009; Smolinski & Colon, 2006). Yet the literature shows very few studies with socially-constructed groups at end of life.

The small amount of research done on socially-constructed groups at the end of life found that members of socially-constructed groups have significantly different care preferences, and different care needs. The differences in care preferences encompassed communication styles and family presence preferences (Freeman & Berger, 2009). These preferences at the end of life are influenced by the socially-constructed group members. Some of the ways these preferences were expressed was through different needs during the decision making processes of advance directive situations and family visiting requests (Freeman & Berger, 2009). While these studies have shown important differences that some socially-constructed cultural groups have at the end of life, the bulk of the extant research does not focus on such groups. Socially-constructed groups have yet to have an opportunity to speak about their needs, desires or lived experiences at the end of life.

The thought that U.S. military Veterans share a distinct culture is a relatively new idea in healthcare research. Those who have conducted research among Veterans have found that there are significant differences. The largest difference that has been found is in terms of quality of life. Quality of life is thought to be comprised of four different kinds of factors; psychological, physical, environmental, and social (Ho, Chiu, Lo & Yiu, 2010; Jacobsen, 2011). U.S. military Veterans, as a socially-constructed culture, have been given little attention in any of these categories. Since considering Veterans as part of a distinct culture is a relatively new idea, only a few studies have been completed in relationship to each of these factors.

Psychological components of quality of life include self-esteem, meaningfulness of life, hope, enjoyment of life and overall psychological health (Ho et al, 2010). U.S. military Veterans' quality of life relative to psychological components has been studied, but the majority of the research centers around their overall psychological health. Multiple studies have been conducted with Veterans to examine their rates of mental illness, most noticeably depression and post traumatic stress disorder (PTSD) (Banerjea, Pogach, Smelson, & Sambamoorthi, 2009; Drapalski, Milford, Goldberg, Brown & Dixon, 2008).

The construct of hope has specifically been studied among Veterans only in relationship to mental illness and suicide attempts (Cancro, 2008; Lysaker et al., 2008). These studies have suggested differences in hope among Veterans compared to their non-veteran peers. Although these studies have laid the groundwork for understanding the differences of hope among Veterans, research with this population has not been extended to the end of life. In fact, no research studies were found in which hope was studied among U.S. military Veterans at the end of life.

### **Significance**

This phenomenological research study aimed to understand the lived experience of hope at the end of life among U.S. military Veterans. The study addressed a gap in nursing literature related to hope at the end of life among U.S. military Veterans.

Ethicists argue that U.S. military Veterans are owed healthcare by the country they have served, even when their military service has ended (Bien et al., 2008; Gross, 2008). Selgeid (2008) proposes that

U.S. military men and women have loyally served their country, and “promote the greater good of society by fighting just wars, making considerable sacrifices and risking life and limb in the pursuit of a higher cause” (p.19). Selgeid continues by saying that military Veterans “deserve compensation from the societies they served. A principal of reciprocity would hold that (because Veterans) have made sacrifices for the sake of society, it is right to expect society to give them something in return” (p. 19).

U.S. military members are monetarily compensated for the risks they undertake while serving. Several ethicists argue that the financial compensation is not often sufficient to attract and retain people who would be considered good recruits for the U.S. military. In a classic article, Sommers (1986) contends that the life of the military service member is unattractive. Troops are often asked to spend extended periods of time away from their families and put themselves in danger, yet they receive relatively little payment. The promise of healthcare, even when the time of active service ends, helps to make the military a more attractive career choice. Levinsky (1986) counters this argument by saying the obligation for society to pay for healthcare for U.S. military Veterans is analogous to a corporation continuing to extend healthcare benefits, free of charge, to a former employee. Yet Sommers (1986) explains that this argument is false in that the military is not comparable to any other type of employment. The risks and sacrifices troops are required to make entitle them to special privileges, even when their time of service ends. Sommers cites Rawls’s (1971) doctrine of universal rights, which ethically argues for life necessities to be provided by those who are responsible for care, such as children are to be cared for by their parents. Sommers (1986) points out that the military supplies all of life’s necessities while troops are actively serving. Providing healthcare for active troops keeps the nation’s defenses physically strong and their morale high. Sommers states, “the responsibility for service-connected disorders is analogous to the responsibility of a corporation to compensate its employees for disabilities acquired on the job” (p. 15). The United States has taken this a step further and has made the choice as a society to provide care for active and veteran military service members. And this choice helps Veterans to maintain health in spite of the risks they endured to protect the nation’s values and beliefs. It is now the obligation of the nation and its citizens to support the healthcare of this group.

Because the U.S. has accepted that military Veterans are owed a debt for their military service, there exists in this country a national system of healthcare for this group. To more fully understand society's commitment to Veterans' healthcare, it is first necessary to understand how the system evolved and what it now entails.

### **Historical Perspective on Veteran Healthcare**

The U.S. Department of Veterans Affairs offers a comprehensive history of Veteran healthcare. According to their website ([http://www1.va.gov/opa/publications/archives/docs/history\\_in\\_brief.pdf](http://www1.va.gov/opa/publications/archives/docs/history_in_brief.pdf)), the United States has provided pensions and healthcare to our military Veterans since the beginnings of the nation in 1776. At that time, the Continental Congress did not have the authority or money to make pension payments or provide care for Veterans, so each state assumed responsibility for its own. The healthcare Veterans received varied from state to state, depending on the monetary resources each possessed. From 1776 to 1808, approximately 3,000 military Veterans received care for a combat-related injury and/or a pension from their home state.

In 1808 the Bureau of Pensions was formed. This agency was the first government sponsored and operated facility to offer healthcare and pensions to military Veterans. At that time, there were approximately 2,200 military Veterans who received their healthcare and pensions through this agency. Following the War of 1812 the number of U.S. military Veterans grew to over 17,000, and by the time the Civil War ended in 1865, there were more than 1.9 million military Veterans. The healthcare needs of Veterans at this time were so extensive that Congress authorized the creation of The National Asylum for Disabled Soldiers. This agency assumed responsibility for the healthcare needs of all U.S. military Veterans, thus alleviating the burden of healthcare from the Bureau of Pensions. The first National Asylum opened in Maine in 1865, and provided room, board, and incidental medical care for wounded military Veterans. During its first year the facility became so crowded with military Veterans seeking medical care that Congress authorized funds to open more nationwide. By 1920 the national Asylums for Disabled Soldiers were elevated to hospital status, yet were still operating independently.

In 1929, all National Asylums were combined into a nationalized system known as Veterans

Affairs (VA) Medical Centers. Today the VA has over 157 medical centers, with at least one in each state, Puerto Rico, and the District of Columbia. The VA also has 900 ambulatory clinics, 136 long-term care facilities, and numerous rehabilitation, treatment, and home-care programs.

([http://www1.va.gov/opa/publications/archives/docs/history\\_in\\_brief.pdf](http://www1.va.gov/opa/publications/archives/docs/history_in_brief.pdf))

In 2012 the VA provided healthcare to an estimated 8.76 million Veterans. ([http://www.va.gov/vetdata/docs/Quickfacts/Homepage\\_slideshow\\_03\\_31\\_13.pdf](http://www.va.gov/vetdata/docs/Quickfacts/Homepage_slideshow_03_31_13.pdf)). Factors that limit Veterans' use of VA facilities include in-accessibility and perceptions that care is poor and only for disabled Veterans. (<http://www.gao.gov/products/GAO-12-12>) Further, the VA has a complex eligibility system for healthcare services. This leads to fewer than a third of Veterans receiving care at VA facilities.

### **Nursing and Veteran Healthcare**

Nurses also have a long standing history of caring for military members. As early as the Crimean War (1853-1856), nurses cared for soldiers injured during combat. Among these nurses were Florence Nightingale and Mary Seacole, who are widely considered to be two of the founders of modern nursing (Mathiasen, 2010). Nurses were also the first staff members of National Asylums for Disabled Soldiers and provided most of the daily care for U.S. military Veterans.

Newman, Sime and Corcoran-Perry (1991) state that the professional discipline of nursing is defined by its social relevance and values orientation. According to the authors, nursing's focus comes from a commitment to society through service and knowledge development. If we as a country value our military Veterans, it is nursing's obligation to build knowledge that is reflective of those beliefs. This research study has developed knowledge about constructs that are relevant to society's values, but not yet fully understood in the discipline of nursing. This study will help to build the discipline of nursing by building nursing science.

Nursing science is described in classic articles to be an organized body of knowledge which is concerned with human phenomena that are specific to the care nurses provide (Phillips, 1996; Schlotfeldt, 1987). Nurses are called to develop relevant knowledge about phenomena in which development is inadequate (Schlotfeldt, 1987). Although the phenomenon of hope has been studied extensively in various

well and ill populations, no literature could be found which examined hope at the end of life in the Veteran population. Knowledge developed from this study builds nursing science and thereby the discipline of nursing.

The discipline of nursing was founded on ethical behaviors and expectations. The American Nurses Association (ANA) developed a code of ethics to be used as a guide for carrying out nursing “responsibilities in a manner consistent with quality in nursing care and ethical obligations of the profession” (Fowler, 2006). One of the ethical standards that governs the discipline of nursing speaks to contributing to the advancement of the discipline through knowledge development. The ANA states that nurses should engage in scholarly inquiry which expands the body of knowledge which subsequently forms the foundation of the discipline. They suggest that ongoing scholarly activities are essential to fulfilling nursing’s obligation to society. Furthermore, Thornburg (1993) whose work on the lived experience of hope suggests “understanding the meaning of health experience, particularly hope, adds to the knowledge about health” (p.3) It can be argued that this knowledge can be very useful to nurses caring for the particular population who ascribe meaning to that phenomenon.

### **Summary**

Research shows that U.S. military Veterans have different experiences and needs throughout their lives, yet little is known about their lived experiences at the end of life. While a small amount of research has been conducted with this cultural group at the end of life, no studies were found in which U.S. military Veterans were able to express perceptions of their lived experiences of hope at the final stage of life. It is nursing’s ethical obligation to expand our discipline’s knowledge about this culture, in hopes of better caring for military Veterans as they experience end of life. This research study aimed to explore and understand the meaning of hope at the end of life among U.S. military Veterans. This study addressed a gap in the literature and contributes to nursing’s knowledge about the construct of hope and the culture of military Veterans.



## CHAPTER 2 REVIEW OF LITERATURE

In this chapter I provide a succinct review of the literature as it relates to the construct of hope, the developmental stage of life known as the end of life, and the socially-constructed culture of U.S. military Veterans. Furthermore the conceptual framework for the study is provided. Some research experts caution researchers conducting qualitative studies to limit their exposure to conceptual frameworks so as not to bias their research with presuppositions and assumptions (Munhall & Chenail, 2008). Others, however, believe it is necessary to provide a brief introduction to the conceptual framework the author is proposing to use so as to justify the study's aims and purposes (Creswell, 2007). Therefore, I will provide a brief introduction to the conceptual framework for this research.

### **The construct of hope**

Hope is a facet of psychological quality of life. The phenomenon of hope is considered to be a positive subjective emotional experience which allows the person experiencing it a positive outlook on life (Duggelby, Williams, Wright, & Bollinger, 2009). Many nursing studies have defined hope as a positive expectation about the future in relationship to one's life goals. The construct of hope has been shown to be exceptionally important during the end of life and positively associated with quality of life during terminal illnesses.

The central construct of this research is hope. According to Miller (2007) hope is a central construct for nursing. The discipline of nursing's knowledge related to this construct comes from multiple concept analyses, instrument testing, and correlative testing of interventions. Previous research has shown the impact hope has on people and importance of hope in everyday lives. Consistently in the literature hope has been shown to be essential to human well being (Hearth, 1992; Miller, 2007), positively associated with quality of life (Duggelby, Williams, Wright, & Bollinger, 2009) and necessary for life itself (Cutcliffe & Herth, 1995; Elliott & Olver, 2009). Nurses are urged to understand hope in patients because of the value people place on it (Elliott & Olver, 2009).

## Defintions of Hope

Hope, or the positive subjective emotional experience which enables people to have a positive outlook on life, has been studied extensively; having first emerged in the healthcare literature in the mid-to-late 1960s. At that time hope was most often associated with spirituality. Lynch's (1965) and Stotland's (1969) research about hope revealed two main attributes of the construct. The first was that hope was the center of a person's spiritual existence (Lynch, 1965). The second was that hope was a necessary emotional reaction that helped people cope with stresses in their everyday spiritual lives (Stotland, 1969). Both authors saw hope as being beneficial and necessary and believed it to have a connection to spirituality. These attributes are still very common in research on hope today. Many authors have found that people believe hope to be intertwined with a sense of spirituality (Basset, Lloyd, & Tse, 2008; Buckley & Herth, 2004; Duggleby, 2001; Johnson, 2007; Neederman et al., 2010; Reder & Serwint, 2009).

Since Lynch and Stotland first researched hope, the construct has been studied very extensively in the healthcare literature. Although participants of various studies described hope in unique ways; common shared meanings have been observed (Elliott & Olver, 2009). Most often hope is associated with a sense of positive expectations (Cutcliffe & Herth, 1995; Herth, 1992; Johnson, 2007), orientation to the future (Buckley & Herth, 2004; Cutcliffe & Herth, 1995; Duggelby, 2001; Elliott & Olver, 2009; Herth, 1992; Johnson, 2007; Miller, 2007; Parse, 1999; Parse, 2007; Reder & Serwint, 2009), and life goals (Buckley & Herth, 2004; Cutcliffe & Herth, 1995; Deuggleby, 2001; Herth, 1992; Johnson, 2007) .

Hope has also been described as being multidimensional (Buckley & Herth, 2004; Cutcliffe & Herth, 1995; Parse, 1999; Reder & Serwint, 2009), dynamic (Cutcliffe & Herth, 1995; Parse, 1999; Reder & Serwint, 2009) and individualized (Cutcliffe & Herth, 1995; Parse, 1999). Most often people speak about having a sense of hope that is personal to them and that involves and influences many different aspects of their lives.

### **Hope at the End of Life**

The construct of hope has been examined extensively in the end-of-life literature. Participants of many studies describe hope at the end of life with the same characteristics and definitions as participants who are not yet experiencing the end of life (Duggelby, 2001; Duggelby and Wright, 2009; Elliot & Olver, 2009). In these studies participants still describe hope within the context of spirituality (Duggelby & Wright, 2009; Herth, 1992), positive expectations, goals, and future orientations (Duggelby & Wright, 2009; Elliot & Olver, 2009; Miller, 2007). Studies also show participants at end of life believe hope to be multidimensional (Herth, 1992), dynamic, and individualized (Elliot and Olver, 2009).

However, when situated within the context of end of life, participants' focus on the characteristics of hope changes. The focus of hope often switches from curative to palliative goals. In the classic article by Duggelby (2001) the author found that hope among terminally-ill participants changed from hope for a cure to hope for a peaceful death. The future to dying participants meant the coming day(s) instead of months or years ahead. Their goals and positive expectations moved outside themselves and involved wishes for their family and friends. To these patients hope was also multidimensional, dynamic, and individualized. The same characteristics and definitions of hope have been noted in multiple studies of hope at the end of life. While hope is still present and important, there is most often a shift in emphasis for terminally ill patients (Duggelby & Wright, 2009; Elliot & Olver, 2009; Johnson, 2007; Miller, 2007).

When nurses have examined the construct of hope among those individuals who are facing the end of life they have frequently done so with quality of life in mind. Several studies have shown how addressing hope at end of life has a positive impact on patients' quality of life (Duggelby, 2001; Miller, 2007; Parker, 2010; Reinke, et al., 2009).

### **Hope among U.S. Military Veterans**

The construct of hope has also been studied among U.S. military Veterans in terms of quality of life. Quality of life is most frequently studied in relationship to the excess burden of mental illness and drug and alcohol abuse that many military Veterans experience (Cancro, 2008; Lysaker et al., 2008).

Although studies have shown a difference in hope between Veterans and non-veteran peers, no study could be found which examined the construct of hope among military Veterans at the end of life.

### **The Context of the End of Life**

My research is primarily concerned with the population of military Veterans who are experiencing serious and life-limiting conditions. Therefore it is important to summarize the current state of the end-of-life literature. The term *end of life* has been defined and used inconsistently in the literature. “End of life” tends to be used synonymously with death and dying (Hall, Legault & Cote, 2010; Parsons, 2010), and for those who are receiving hospice and palliative care services (Crang & Muncey, 2008; Jablonski & Wyatt, 2005; Johnson, 2007; Pierson et al., 2002). There are also definitions that give time frames to the estimated length of life. Some time frames have the end of life period to be less than six months of estimated life (Hermann, 2007; Jablonski & Wyatt, 2005), to the last days, hours, or minutes of life (Crang & Muncey, 2008; Jablonski & Wyatt, 2005; Johnson, 2007; Pierson et al., 2002). Ferrell & Coyle (2006) state that advances in healthcare have changed the trajectory of dying. The length of an average life has become longer, infant and childhood mortality has decreased, and fewer people are dying from acute illnesses. Because of these factors, the end of life varies greatly from person to person, which makes the period of end of life difficult to define. For this research study a person was considered to be at the end-of-life period if they had been 1) diagnosed as having a terminal illness and was 2) receiving hospice services. The rationale for this definition is because this is this is the definition that most U.S. hospice programs use to refer to terminally ill patients.

In addition to being broadly defined, end of life is also viewed as multifaceted. The literature includes different facets of end of life that are commonly identified by individuals who are dying. The most commonly mentioned facets of end of life which participants mention are the meaning of death (Bohland, 2010; Lowton, 2009), care preferences (Mack, et al., 2010; Matsui & Braun, 2009), communication (Szmuiłowicz et al., 2010), quality of care (Afzal et al., 2010; Seow et al., 2009), and quality of life (Grant & Sun, 2010).

## **The Population of U. S. Military Veterans**

It is essential to study hope at the end of life in the Veteran population because they represent an expanding cultural group with unique needs that are not yet known. However, there seems to be a lack of consistency in the literature as to how to identify Veteran status. Most studies that have been conducted with military Veterans ask participants to self-identify their Veteran status, simply asking the person if they are a Veteran (e.g. Duffy, Ronis, Fowler, Schim, & Jackson, 2006; Freeman & Berger, 2009; Maugen, Ren, Bosch, Marmar, & Seal, 2010).

## **U.S. Military Veteran Service Characteristics**

It is also important to consider that not every Veteran was engaged in the same type of service. The VA categorizes Veterans according to their branch of service, rank, and the conflict during which they served. It is estimated that there are currently 22.2 million U.S. military Veterans. The service branch with the highest percentage of military Veterans is the Army, with 9.6 million Veterans (43.2%). The U.S. Navy and the U.S. Air Force have 4.9 million (22%) and 4.1 million (18.4%) Veterans respectively. The Marines Corp has approximately 2.3 million Veterans (10.3%). The remainder of the 1.3 million (6%) U.S. military Veterans are people who served in the various reserve forces. (Table 1) The rank that the Veteran held at discharge from the military is recorded by the VA as either *officer* or *enlisted person*. Of the 22.2 million military Veterans approximately 1.5 million were officers and approximately 20.7 million were enlisted. (va.gov).

The conflict during which Veterans served is also important. Of the 22.2 million military Veterans who are alive today, 2.2 million (9%) served in World War II, 2.6 million (12%) in the Korean Conflict, 7.6 million during (34.5%) the Vietnam era, and 5.5 million (25%) in the Gulf War. The other 4.3 (19.5%) million military Veterans served during defined peacetimes. (Table 2) (<http://www.census.gov/compendia/statab/2011/tables/11s0518.pdf>) Official census data was not available to verify the distribution of Veterans of Operation Iraqi Freedom (Iraq) and Operation Enduring Freedom (Afghanistan).

Table 1

*U.S. Military Veterans According to Branch*

Branch of Service	Number of Veterans (million)	% of Total Veteran Population
Army	9.6	43.2
Navy	4.9	22
Air Force	4.1	18.4
Marines	2.3	10.3
Reserve Forces	1.3	6

\*Numbers are rounded to nearest 1/10 million and ½ %

Table 2

*U.S. Military Veterans According to Service Era*

Service Era	Number of Veterans (million)	% of Total Veteran Population
World War II	2.2	9%
Korea Conflict	2.6	12%
Vietnam	7.6	34.5%
Gulf War	5.5	25%
Peacetime	4.3	19.5%

\*Numbers are rounded to nearest 1/10 million and ½ %

Demographics are also recorded on the age, gender, and race/ethnicity of U.S. military Veterans. The data show military Veterans range from less than 20 years old through Veterans who are 85 years and older. Current demographics show the age cohort with the highest percentage of Veterans is those who are between the ages of 60 and 64, at approximately 3.4 million Veterans (15.3%). Of the total population of military Veterans, only 1.8 million (8%) are female. Racial and ethnic statistics show that Caucasians represent the highest percentage of military Veterans, at approximately 17.4 million people (78.3%). African Americans are the second highest percentage of military Veterans at approximately 2.5 million people (11.2%).

Another factor that is considered significant among this population is whether the person was a combat or a non-combat Veteran. A combat Veteran is a military member who served in a *combat forward* area near active fighting (Atwater, 2009). Combat Veterans are likely to have shared traumatic experiences which affect them for the rest of their lives (Hobbs, 2008). In classic work with Vietnam combat Veterans, Lifton (1972) states that combat Veterans' "overall psychological task is that of finding

meaning and justification in having survived and in having fought and killed” (p. 2).

### **Combat Veterans**

Military combat Veterans have higher rates of Post Traumatic Stress Disorder (PTSD) and physical injuries when compared to their non-combat Veteran peers. PTSD is an anxiety disorder that can occur after witnessing a traumatic event. The associated symptoms of PTSD include re-experiencing the event, avoidance, withdrawal, and hyperarousal (<http://www.ptsd.va.gov>). The National Center for PTSD (2008) estimates that 55% of all Americans, regardless of their military service, have had at least one traumatic event in their lives, and roughly 8% of them develop PTSD as a result. Of all the combat Veterans who survived the conflicts of World War II, Korea, and Vietnam, 30% are estimated to have PTSD (Sayer, et al., 2010;). The sequellae of PTSD for combat Veterans often negatively affect multiple areas of their lives, including social relationships, employment, marital status, and quality of life (Sayer, et al., 2010; Spont, Murdoch, Hodges & Nugent, 2010; Teten, 2010).

### **The Culture of the Military**

Cultures are classically defined as traditions and customs, transmitted through learning, that govern the beliefs and behaviors of the people exposed to them (Kottak, 1991). Kottak states that humans adapt to, or cope with stressful situations and environmental stressors by drawing on learned cultural practices. In her seminal work on culture, Leininger (1991) states that cultures are “the learned and transmitted values, beliefs, and practices that provide a critical means to establish culture care patterns from people” (p. 36). Leininger’s work, which was built from an anthropological perspective, focuses on cultures whose attributes are acquired through living in a particular society, rather than through biological inheritance (Schim et al., 2007). This expands the idea of culture beyond racial and ethnic groups, to include *communities of interest*. Schim et al, (2007) explain communities of interest as groups of people who share particular interests, such as the elderly, persons with disabilities, and cancer survivors. Kottak (1991) refers to communities of interest as socially-constructed cultures. Such socially-constructed groups are also commonly termed *sub-cultures* because they coexist within larger cultural groups. In this research, I am using the broader term, *culture*, when referring to the beliefs, values, and patterns of

Veterans generally and the term sub-culture when discussing more specific groups such as Marine Corp Veterans, combat Veterans, or female Veterans.

Kottak (1991) suggests that people construct culture in a variety of ways. Culture is learned, shared and symbolic and is learned through direct observations and instructions of the cultural group. Culture, in terms of norms and behaviors, is shared by expert members of the group with novice members. In most ethnic and racial groups experts are adults and novices are children. However, in socially-constructed cultures, experts are those who have been members of the culture for a longer time (e.g. a cancer survivor of ten years) teaching a novice member (e.g. a cancer survivor of two years). Expert members share their experiences with novice members and thus through sharing, help novices learn the culture. The symbols of a culture, both verbal and nonverbal, are also taught to members new to the culture. Verbal symbols might include special linguistic terms or meanings, jargon, prayers, creeds or mottos which are important to the cultural group. Nonverbal symbols include body posture, eye contact, and other ways of nonverbally communicating, such as facial expressions and gestures. All of these are taught to novice members of the culture and through this process new members learn about the beliefs, norms, and behavior patterns and are slowly integrated or assimilated into the culture (Kottak, 1991).

One prominent socially-constructed culture in society is the U.S. military. Hall (2011) states, “the unique culture of the military is, indeed, a diverse group of people in American society that must be understood as uniquely different from the civilian world” (p. 4). Other authors who have studied U.S. military members agree with Hall on this point (Fennel, 2008; Reger, Etherage, Reger & Gahm, 2008). As part of a culture into which members are assimilated, members of the military, both active and past, must be cared for within that context. Dass-Brailsford (2007) states, “all experiences originate from a particular context; and (healthcare workers) must be attentive to this context and the role that cultural identity plays in a client’s life” (p. 22). The behaviors and norms of the military culture are instilled in its members during basic training, reinforced during the time of service, and ultimately strengthen the soldier’s ability to survive during training exercises and missions (Lunasco, 2010).

Several characteristics unique to the military culture have been identified. In a classic article



Wertsch (1991) identified common characteristics of the culture of the military to be: isolation from loved ones, relocation of household, rigidity and conformity to military rules, detachment from civilian life, social effects of rank on family, and lack of control over pay and promotion. Wertsch contends that these characteristics are unique to the culture of the military and different from the democratic society of most citizens of the United States. Wertsch reflects, “the great paradox of the military is that its members, the self appointed front-line guardians of our cherished American democratic values, do not live in democracy themselves” (p. 15). These characteristics profoundly influence the needs and experiences U.S. military members have during their service lives and once their time of service ends (Hall, 2011).

When military service ends the former military member becomes known as a Veteran. The literature has shown that some U.S. military Veterans identify more strongly with their Veteran status than do others. People with strong military affiliations are more likely to use the VA healthcare system, more likely to participate in Veteran social groups, and are more likely to closely affiliate with *Veteran culture* (Hobbs, 2008; Rabb & Ban, 2010). Hobbs (2008) supported the idea that Veterans have a unique culture which includes language, symbols, and places where they gather and talk about things specific to their experiences. This culture is also informed by shared experiences that are rooted in traumatic events. To address those specific needs of what is seen to be its own unique cultural group, the VA has coined the term *Veteran-centric care* (unknown author, 2010, pg. 10) which focuses specifically on the needs of patients within the context of Veteran culture (Hobbs, 2008; NHPCO.org/Veterans).

### **Veterans at the End of Life**

There is a growing body of literature related to military Veterans’ end-of-life experiences. This literature suggests certain preferences that Veterans seem to share when dying, regardless of their age, ethnic group, or other cultural factors. As a cultural group Veterans have been reported to be very homogenous in terms of their end-of-life care preferences (Fischer, Kutner, Sauaia & Kramer, 2007; Lu, et al., 2010). These care preferences include a desire for control over death (Fischer, et al, 2007; Rodriguez & Young, 2006), high rates of do- not-resuscitate (DNR) orders (Duffy, et al, 2006; Freeman & Berger, 2009), preferences for open and honest communication from physicians (Duffy, et al, 2006;

Freeman, 2009; Rodriguez & Young, 2005), and ambivalence regarding family and friends being present at the time of death (Duffy et al., 2006; Freeman & Berger, 2009). However, no published literature was found in which U.S. military Veterans actually facing end of life were able to give voice to their thoughts and feelings . Schim et al. (2007) contend that “the ways in which people experience and interpret the world are largely determined by the cultural contexts they inhabit” (p. 104). Although some research of Veterans at the end of life does exist, no literature could be found in which the Veterans’ voices were expressed about hope or any other phenomena important at the end of life. If nurses are to understand the lived experiences for Veterans at the end of life and tailor nursing care to their specific needs, research which gives voice to these unknown entities must be conducted.

### **Summary**

The construct of hope at the end of life has been studied by nurse scientists. However, there remains a gap in scientific knowledge about hope at end of life among socially-constructed cultures such as U.S. military Veterans. While previous research has shown that Veterans have different experiences throughout the course of their lives, very little attention has been given to the lived experiences of this culture at the end of life. This study aimed to fill those identified gaps and expand nursing’s scientific knowledge of hope at the end of life.

## CHAPTER 3 METHODOLOGY

### Method of Inquiry

The aim of this study was to explore and understand the lived experiences of hope among U.S. military Veterans at the end of life. I used a phenomenological method, which is an inductive research process, to achieve the aim of the study. Before the applied method of inquiry is discussed, and each step of the research process is presented, a brief introduction to phenomenology is provided.

### Central Structures

Phenomenology is a method of inquiry which is comprised of four central structures. These are paradigms, lived experiences, consciousness, and intentionality. Phenomenological research seeks to describe the meaning for several individuals of their lived experiences with a concept or a phenomenon. Creswell (2007) explains that this type of research is informed by a social constructivism worldview or *paradigm*; in which individuals seek understanding of the world by developing subjective meanings of their life experiences. These subjective meanings are known as *lived experiences* and they often vary substantially from how others perceive the world. Researching a phenomenon with this method leads the researcher to investigate the complexity of individual worldviews rather than focusing on narrow meanings or ideas.

Consciousness and intentionality are linked in what Husserl (1964) calls the *intentionality of consciousness*. Consciousness must be “recognized as a self-contained system of being” (p. 153) and is always directed towards an object. Reality or the subjective meaning of the object is related to one’s consciousness of it and cannot be divided into subjects and objects. Subjective realities, according to Husserl, are the only realities that exist and they are individualized. Essentially this means that each person’s reality is slightly different from everyone else’s and that individual reality, based on individual perceptions and experiences, is the only one which exists for the person.

This phenomenological study was informed from the simultaneity paradigm; in which reality is subjective and individualized (Parse, 1987). Ontology in this paradigm contains multiple realities and truths. Multiple interpretations are possible for all events and the focus of an inquiry guided by this

paradigm is to identify less obvious meanings and the messages that occupy the margins. Discourse or language as well as non-verbal actions and behaviors are all considered to be vital. In this research context knowledge comes from talking with or interviewing people (Rogers, 2005). Creswell (2007) states the purpose of phenomenology is to “reduce individual experiences with a (construct) to a description of the universal essence” (p. 58). According to Husserl (1964) phenomenology is concerned with describing the acts and experiences of people and not the causal explanations of events. Therefore the overall aim of this study was to understand common and unique individual meanings of the lived experiences of hope at the end of life among U.S. military Veterans.

### **Assumptions**

As a research method, phenomenology was first used in the late 1800s to enhance understanding of human experiences (Parse, 2001; van Manen 1990). There are three basic assumptions that underpin phenomenology as a method (Parse, 2001). The first assumption is that humans co-constitute situations. In other words, humans act with their environment to create situations together. This assumption encompasses the idea that humans and their environments are inextricably linked. Therefore according to this methodology, researchers cannot manipulate one against the other. An example of how an environment might be manipulated against person might be a researcher studying the effects of sleep deprivation on stress and coping responses. Although the subject of this research is relevant to understanding stress and coping responses in certain situations it could not be studied using a phenomenological methodology as the researcher would need to manipulate the patient and their environment separately. This type of research would not align with the first assumption of phenomenology that the person cannot be separated from his/her environment.

The second assumption of phenomenology is that “knowledge about human experiences is expanded by allowing essences of phenomena to appear through descriptions without predictable prescriptions” (p. 78). Phenomenological studies aim to describe not only what participants have in common as they experience a phenomenon but also the unique meanings each person has for the phenomenon. Therefore, the fundamental purpose of this approach is to reduce individual experiences

with a phenomenon to a description of “the universal essence” (p. 58). In other words, the researcher conducting phenomenological research strives to describe the essences or the qualities which are fundamental to that phenomenon. This is done first by describing the unique ways that participants describe a phenomenon. For example, if a researcher is using a phenomenological method to understand the experience of post-traumatic stress disorder (PTSD), he or she might interview several participants who have this diagnosis. The researcher would then describe all the unique ways in which participants described PTSD, such as “feeling anxious” “worried all the time” and “reliving events”. The researcher then takes those descriptions and combines similar ideas among participants. This combining of similar ideas leads to a description by the researcher of what participants deemed to be the essence, or the qualities which encompassed, PTSD to them. Essences are thought to be “the grasp of the very nature of something” (van Manen, 1990, p. 177), and that “which makes man what he is” (Heidegger, 1959, p. 140).

The third assumption of phenomenology is that knowledge about human experiences can be gained by the researcher studying retrospective descriptions of lived experiences of phenomena. Therefore, phenomenological researchers conduct interviews with participants and then study the verbatim transcribed scripts as data with the overall purpose of gaining knowledge from the texts about the phenomenon. The purpose of phenomenology is to explore and understand the structures of lived experiences in order to shed light on the essence of the phenomenon under study (Parse, 2001). Researchers who use this method strive to uncover the data rich patterns or structures of essences of phenomena which are described by participants who are living with the phenomenon. Van Manen (1990) states, “We are able to recall and reflect on experiences thanks to language. Human experience is only possible because we have language” (p. 38). Thus the focus of phenomenology is the language, both verbal and nonverbal that the participant uses to describe his or her lived experience of a phenomenon.

### **Primary Types**

There are two primary types of phenomenology. They are hermeneutic and psychological phenomenology (Creswell, 2007). Both types of phenomenology are concerned with lived experiences

and have the goal of creating understanding of phenomena, yet their methods are different. Each phenomenological approach operates under the philosophical assumption that each participant's reality, "is simply one of many world views" (Laverly, 2003 p. 8). Laverly describes hermeneutic phenomenology, as pioneered by Heidegger, to be focused on the translated or "situated meaning of the human world" (p. 7). Interpretations by the researcher are seen as a critical process of understanding lived experiences. In hermeneutical phenomenology the interpretative process begins with an interview of the participant, an interpretation of the verbatim transcribed interviews by the researcher and then verifying the interpretations with the participant. This process, known as the *hermeneutic circle*, is recursive and relies heavily on the interpretations of the researcher. Hermeneutical phenomenological research is prevalent in the nursing literature (Charalambous, Papadopolus & Beadsmoore, 2008; Yousefi et al., 2009). Psychological phenomenology is focused less on the interpretations of the researcher and more on the description of participants' lived experiences (Creswell, 2007). Laverly (2003) describes the primary focus of psychological phenomenology as phenomena as they appear through consciousness. Husserl (1964) described psychological phenomenological research as conducting a dialogue with participants in which each person described his or her meaning of a phenomenon. This meaning is co-constructed between the individual and their environment. In psychological phenomenological research the researcher interviews the participants and uses the verbatim transcribed texts to describe the participant's lived experience of the phenomenon. There is little interpretation in this method. Psychological phenomenology is also a very common method employed in nursing research (Kleinman, 2004; Leisniak, 2010). I used a psychological phenomenological research design in this study to understand the lived experiences of hope at the end of life among U.S. military Veterans because the primary focus of this methodology is to understand participants' lived experiences with a particular phenomenon

### **Challenges**

There are two primary challenges with phenomenology. The first stems from the requirement that phenomenological researchers must suspend their beliefs and assumptions about constructs before proceeding with research. Husserl (1931) referred to this process as *epoche* or *bracketing*. Creswell

(2007) explains bracketing as a process by which investigators set aside their own experiences with a phenomenon in order to reduce investigator bias about the phenomenon. By bracketing their own assumptions about a phenomenon, researchers avoid allowing their own beliefs and perceptions to unduly influence the participant interviews, data analysis, and ultimately the study findings. Bracketing quite often is approached with a reflexive journal in which the researcher documents personal thoughts and feelings prior to and following each interview. Using such a journal helps reduce bias between interviews and throughout the research process. The thoughts in the journal are not analyzed in data analysis per se; they are simply meant to keep the researcher's thoughts from unconsciously biasing the research study. However, several phenomenological researchers have challenged bracketing as a process that is nearly impossible to fully achieve (Laverly, 2003; Van Manen, 1990). Recommendations to novice researchers using a phenomenological method are to bracket assumptions at the beginning of the research process, before every interview, after every interview, and while completing data analysis (Creswell, 2007). Although perfect bracketing might not be achieved, researcher bias can be reduced through the use of bracketing assumptions during the course of the study.

The second challenge researchers face when using a phenomenological method is that getting the essence, or the essential qualities of the phenomenon, of the lived experience from an individual in just one interview can be difficult. Creswell (2007) states this can be especially challenging for novice researchers or researchers new to this method. However, Creswell does identify ways in which novice researchers can minimize this risk. One recommendation is using a research journal or field notes to capture thoughts and non-verbal communications from the participant immediately after the interview. In this way the researcher can capture findings essential to the essence, the defining qualities, of the phenomenon which might not have been verbalized by the participant at the time of the interview. For instance, if a person began to silently cry during the interview but did not speak about distress, the researcher would want to make note of this. Crying, while not verbally acknowledged by the participant, could be important to the essence of the phenomenon. Another recommendation Crewsell (2007) has for gleaning the essence of the phenomenon in single interviews is to have novice researchers work closely

with a research mentor, or expert in the method to ensure that research questions are worded to elicit the essence of the phenomenon. During this study I use a reflexive journal to bracket assumptions and to record thoughts immediately before and after all interviews, as well as during the data analysis process. I also worked closely with my dissertation committee advisor who served as an expert research methodologist.

Despite identified challenges phenomenology has been used quite successfully to examine a number of different nursing phenomena, including hope. Parse's (1999) book is a compilation of work by authors who have studied the lived experience of hope in various international populations such as Canadians with chronic illness (Parse, 1999), well people in Finland (Toikkanen & Muurinen, 1999) and well elders in Japan (Takahashi, 1999) and Sweden (Willman, 1999). The phenomenological method has also been used to study the lived experiences of hope among individuals with infertility (Su & Chen, 2006), parents whose infants died with sudden infant death syndrome (Thornburg, 1993) and patients living with cancer diagnoses (Benzein, Norberg & Saveman, 2001). This method allows for the phenomenon of hope to be studied in various populations among those who are well, ill, or who have experienced a loss.

### **Method of Inquiry: Applied Generally**

Spielberg (1982) and Creswell (2007) identified the essential processes of psychological phenomenology. There are some common modifications that are also widely used. Here I will summarize the process of psychological phenomenology and briefly explain common modifications I used. Spielberg and Creswell explain that the entire method of psychological phenomenology is recursive rather than linear. Therefore, researchers must move back and forth between the steps of the research process multiple times. Recognizing the recursive nature of this methodology, for the purposes of this paper each step will be discussed in sequence.

### **Determining if Research Problem is Suited to Phenomenology**

The first step the researcher needs to do is to determine if the research problem is best suited to a phenomenological method. According to Creswell the type of problem which is best suited for



psychological phenomenology is one in which it is “important to understand several individuals’ common and/or unique experiences of a phenomenon” (p. 60). Importance of understanding is determined to be either a need to develop policy or procedures where existing ones are lacking, or to develop a further understanding of the phenomenon because a group or subset of the population has not previously been studied. While hope at the end of life is a common theme in the literature, no research was found which addressed hope among U.S. military Veterans at the end of life. Hope has been studied among U.S. military Veterans during times of illness, but not at end of life and only in relationship to mental illness and suicide attempts (Cancro, 2008; Lysaker et al., 2008). The study of hope among U.S. military Veterans has not been previously extended to end of life. This gap suggested that the voice of this important and growing socially-constructed cultural group has yet to be heard and that there could be benefits to studying U.S. military Veterans’ perceptions of hope.

### **Identifying the Problem of Interest**

The second step in the applied method is to identify the phenomenon of interest. The phenomenon of interest is clarified so that two similar concepts are not studied concurrently. In their classic article, Morse, Mitcham, Hupcey and Tason (1996) describe five ways in which constructs can be differentiated. Morse et al.’s (1996) five criterion are for the researcher to provide 1) clear definitions, 2) characteristics, 3) boundaries, 4) preconditions, and 5) outcomes of constructs.

The common definitions and characteristics associated with hope are 1) a sense of positive expectations (Cutcliffe & Herth, 1995; Herth, 1992; Johnson, 2007), 2) orientation to the future (Buckley & Herth, 2004; Cutcliffe & Herth, 1995; Duggelby, 2001; Elliott & Olver, 2009; Herth, 1992; Johnson, 2007; Miller, 2007; Parse, 1999; Parse, 2007; Reder & Serwint, 2009) and 3) life goals (Buckley & Herth, 2004; Cutcliffe & Herth, 1995; Deuggleby, 2001; Herth, 1992; Johnson, 2007) .

The third criterion according to Morse et al (1996) is to show which construct the phenomenon of interest is closely related. Hope is most closely related and with which hope shares a boundary is spirituality. Lynch (1965) and Stotland (1969) first described hope as being both the center of a person’s spiritual existence (Lynch, 1965) and a necessary emotional reaction that helps people cope with the

stresses in their everyday spiritual lives (Stotland, 1969). Both authors' research demonstrated that hope is beneficial, necessary, and closely associated with spirituality. The idea that hope shares a boundary with spirituality is still common in the literature. (Basset, Lloyd, & Tse, 2008; Buckley & Herth, 2004; Duggleby, 2001; Johnson, 2007; Neederman et al., 2010; Reder & Serwint, 2009).

Preconditions are Morse et al's (1996) fourth criterion in delineating constructs and are instances which must occur before the construct can emerge. The preconditions of hope are clearly described in the literature as are the definitions and boundaries. Many maintain that everyone can and does experience hope, implying there is no precondition associated with the construct. Parse (1999) terms the construct to be a universal lived experience, meaning that all people are capable of having hope.

The final criterion according to Morse et al. (1996) is the consequences or outcomes that occur as a result of the construct. The most reoccurring documented outcome of hope is quality of life. Having hope has been shown to positively influence participants' quality of life (Duggleby & Wright, 2007; Parker, 2010; Reinke, Shannon, Engelberg, Young, & Curtis, 2010). According to the criteria established by Morse et al, hope is a well defined construct and has been differentiated in the literature from constructs considered similar to it.

### **Data Analysis**

Once the need for the research has been established and the phenomenon of interest has been identified, the research process occurs. The research activities and procedures of this research study will be discussed in detail later in this section. Following the completion of all research activities and procedures the psychological phenomenological researcher investigates the phenomenon of interest by thorough data analysis. This third step involves three sub-steps, which are called intuiting, analyzing, and describing. *Intuiting* is the process of coming to know the phenomenon as it has been described by the participants. In this sub-step the researcher reads and rereads the texts of the interviews, becoming immersed in the data in order to understand the nuances of the phenomenon as described by each participant. Intuiting is a recursive process which requires the researcher to be familiar with several interviews at once. Once all of the passages of the interviews have been read and reread several times, the

researcher begins the second sub-step and analyzes the descriptions. The purpose of *analyzing* is to determine the distinguishing characteristics of the phenomenon so that the researcher can understand the whole of participants' lived experiences. In this sub-step the author, often times with the help of qualitative data analysis software, finds common and unique distinguishing characteristics of the phenomenon as described by the participants. Once data has been analyzed the researcher describes. *Description* requires the researcher to tune into the major manifestations of the phenomenon and begin to form the essences. These essences describe central aspects of participants' lived experiences with the phenomenon.

Spielberg (1982) and Creswell (2007) describe the researcher's fourth step as sorting the essential relationships of the essences. In this step the researcher begins to sort relationships within a single essence and among essences. The purpose of this step is to discover the nature of the general essence. When describing the essential relationships, the researcher also dwells with the descriptions of all participants and pays particular attention to anything that might not have been noticed previously. In this way the researcher is attempting to ensure that essential elements of the lived experiences as described by participants are included in analysis.

Once the essential relationships of the phenomenon have been identified, sorted, and described the researcher begins to construct an interpretation of the phenomenon. This is done through combining essential relationships, establishing essences and overarching themes. The construction of a phenomenon is significant to its meaning. Further, knowledge of the phenomenon expands the researcher's understanding of its overarching meaning.

Finally the researcher interprets the concealed meanings of the phenomenon. In this last step the researcher searches for hidden and disclosed meanings that might not have been overtly stated by the participant. Here the researcher may refer back to nonverbal communication documented in the research journal after the interviews which may uncover additional meaning(s) to the phenomenon. All of these research steps are completed within the recursive Hermeneutic Circle. As the researcher reads the texts of

transcripts she is also interpreting the meaning of them. By completing all of these steps the researcher is constructing and articulating the meaning of the lived experience of the phenomenon.

### **Method of Inquiry: Applied to this Research**

This research study was a psychological phenomenological study in which I employed Giorgi's procedural modification of Creswell's method. Giorgi's (2000) modification for descriptive psychological phenomenological research begins with the same steps described by Creswell (2007) and Speilberg (1982). Once a problem has been identified and justified, and research data has been collected, the researcher dwells with the participants' descriptions. The process of *dwelling* involves reading and rereading the texts of the interviews in order to realize a sense of the whole and the particular nuances of each. It is important to note that Giorgi's (2000) steps are also recursive and a researcher is encouraged to move back and forth between the steps. The second step of Giorgi's procedural modification is to return to the participants for elaboration on areas and descriptions that may be ambiguous. Although this step helps support trustworthiness, in this study it was not included. Rationales for omission of this step included that my participants were nearing the end of their lives. For many people, by the time they are referred and enrolled in hospice programs, they are very near death. In fact, the majority of hospice patients in the US die within 72 hours of program admission (NHPCO.org). It was a challenge to contact and set up visits with Veterans enrolled in hospice care while they were still able and willing to participate in the study. I did not plan to re-contact those I interviewed due to the high probability that they could have become unable to communicate or may have died before the second contact. I was also aware of the need to demonstrate sensitivity to issues of potential burden for both Veterans and their end-of-life caregivers and family members. In consultation with my research faculty advisors, I chose to limit my engagement with each Veteran in the study to one visit and in-depth interview.

The third step in Giorgi's procedural modification is to identify the natural meaning units of the data. *Natural meaning units* are obtained through intuiting, analyzing, and describing as outlined by Spielberg (1982) and Creswell (2007) and are the context-laden descriptions of the phenomenon as revealed by the participant. For instance a participant may describe hope as helpful to his or her everyday

life, linked with religion and promoting/allowing optimism. Each of these descriptions of the phenomenon are separated from one another and placed under an overarching heading. Because the researcher does this with each participant's interview, this step is usually facilitated by the use of qualitative data management software such as QSR International's Nvivo10™. Once the researcher identifies all of the natural meaning units, they are sorted under subheadings. The subheadings are stated in a few words that the researcher believes describes all participants' interpretation of the phenomenon. For the above example subheadings names might be *Everyday Life*, *Religiosity*, and *Optimism*. These subheadings, once labeled in the researcher's own words become known as *focal meaning units* and are the researcher's interpretation of the participants' experience with the phenomenon. The researcher then synthesizes common focal meaning units and forms general structured descriptions. General structured descriptions are a synthesis of the phenomenon and answer the research question about the lived experiences of the phenomenon. Finally, all general structured descriptions are synthesized and the researcher provides a general description or summation of the meaning of the participants' lived experience with the phenomenon.

### **Rationale for Selection of Methodology**

Creswell (2007) uses six characteristics to describe qualitative approaches and help researchers choose which one is best suited to use in their own research. The first of these is the focus of the approach. The phenomenological approach is employed to understand the essence of lived experiences of multiple individuals. Therefore the focus is on understanding multiple experiences with the phenomenon. The second characteristic is the type of problem that is best suited to each approach. When the researcher's question requires the need to describe the essence of lived phenomenon a phenomenological approach is the best design. An example of a research question best suited for a phenomenological study as stated by Creswell is "What meaning does (this group) with a diagnosis of AIDS ascribe to their illness" (p. 108)? This question implies that individuals diagnosed with AIDS have something in common that provides meaning in their lives. For this study, the question can be rephrased as, what meaning do U.S. military Veterans experiencing the end of life ascribe to the construct of hope?

Creswell (2007) describes the other qualitative approach characteristics to be the unit of analysis, data collection forms, data analysis strategies, and the written report. The phenomenological approach is used to study selected individuals who have a shared experience. Data collection approaches may include interviews, documents, observations, and art. Although direct observations, art, and documents are all valid ways to collect data, I chose to use my research experience and expertise and to focus on personal in-depth interviews. In phenomenology collected data are analyzed for significant statements, meaning units, textural and structural descriptions, and descriptions of the essence. In this study I worked to understand the meaning of the lived experiences of hope at the end of life among U.S. military Veterans. Phenomenological data analysis allowed me to begin to answer the research question. In phenomenology the written report describes the essence of the lived experiences for the participants and in my study this dissertation is a reflection of the study's purpose and research question.

Considering all of these criteria is important when choosing an approach to be used in research. My goal lay in understanding the meaning of hope at the end of life among U.S. military Veterans. I needed to understand how people in this culture lived the experience of hope at the end of life in order to address –specific needs for end-of-life nursing care. The primary focus of this research was hope and its structured meaning. Although the meaning was structured by Veterans who are themselves experiencing end of life, the focus of the research was on hope and trying to understand the meaning these participants placed on the phenomenon. The type of research which examines the meaning of phenomena as constructed by individuals is best suited to psychological phenomenological research (Creswell, 2007; Parse, 2001).

## **Research Activities and Procedures**

### ***Setting***

The setting for this study was the homes of U.S. military Veterans enrolled in Hospice of Michigan home services. Each home environment was different and I conducted each interview in a room that was both comfortable and safe for the Veteran and me. Conducting the interviews at participants' homes had both practical and methodological advantages. Since Veterans were identified through a

hospice home care program and were, by definition, nearing end-of-life, it made sense to bring the study to the participants rather than having them engage in difficult or impossible travel outside their homes. Home visits also allowed me to see the physical contexts in which participants were spending their remaining time along with the people and artifacts with which they surrounded themselves.

### *Sample*

Participants in this study were U.S. military Veterans who had been diagnosed as having a terminal illness and who were receiving home hospice services from Hospice of Michigan. A purposeful sampling procedure was used to recruit 7 knowledgeable key informants. The sample size was consistent with common practice in phenomenological research and was kept small so as to provide in-depth data-rich interviews. The time frame for participant recruitment was three months.

Participants had to be 1) receiving home hospice services through Hospice of Michigan, 2) a self-identified U.S. military Veteran, 3) fluent in English, 4) aware of the terminal diagnosis, 5) willing to discuss the experience of having hope while dying, and 6) have a mini cognition test (Mini-Cog) score of at 2 with a Normal Clock Drawing (CDT) or 3 (Negative screen for dementia) indicating alertness and the presence of functional memory. The Hospice of Michigan Research Coordinator referred potential participants to the study. Because of the coordinator's regular interaction with the clients in Hospice of Michigan, the research coordinator was able to screen out clients who had signs of progressive dementia, a current problem with violence, or other behavioral problems. A self-identified U.S. military Veteran was considered to be a person who stated that he or she had served in any branch and at any rank in the U.S. military. Military history of the Veterans was collected via the Military History Checklist. This tool is a 5 question instrument which national hospice programs use as part of their intake process. Information gained from this tool relates to service details such as rank, branch, era served, and general perception of the military experience. I used the Military History Checklist in this study to collect demographic data only, not as a tool to determine eligibility criteria.

Other adult family members were present during my interviews with the Veterans. Each Veteran was given the option to have others stay in the room during the interview or to be interviewed alone.

However, family members were not considered participants in this study as the goal was to understand specifically the Veterans' perspectives of hope at the end of life. When people other than the Veteran interjected comments during the interview, I politely redirected the conversation back to the key informant. No material for the study was collected about or from family members who were incidentally present.

Exclusion criteria were based around the consideration that phenomenological research often requires participants to engage in long in-depth interviews. Although the length of the interview was determined by the participants' responses to focused questions, a general guideline of one to two hours is common in phenomenological research (Spezial & Carpenter, 2007). Available literature suggests that the length of interview for palliative care patients can also be from 60-120 minutes without additional risk (LeBlanc et al., 2010; Sheehan, 2010). Exclusion criteria were as follows: 1) Veterans who were unable, due to the nature of their illness or present condition, to engage in a 60-120 minute interview and 2) individuals who had dementia or other cognitive impairment, which hindered their ability to participate in an interview as determined by a score of 0 (Positive for cognitive impairment) or 1-2 Abnormal Clock Drawing or CDT) or 1 (Normal CDT) on Mini-Cog test. 3) Since these were in-home interviews, patients with current behavioral or violence problems were also excluded at the recommendation of the research coordinator.

During the interview process I, as a nurse with more than 10 years of clinical care experience, vigilantly monitored each Veteran. If the Veteran became too tired to continue the interview, I would have ended the session. None of the Veterans expressed or exhibited fatigue during the interviews. During one interview a participant did excuse himself for a moment to use the bathroom, but requested that research interview continue once he returned. I also monitored each Veteran for signs of psychological distress, such as emotional distress from sharing their stories. Some Veterans did shed a few tears or seemed mildly upset when telling stories about their service. When this occurred I offered to stop the recordings, but all of the Veterans declined the offer. By the end of the interviews the Veterans who had



displayed signs of mild distress appeared at ease. I did not need to refer anyone back to their hospice team for follow up on concerns.

### ***Human Subjects Considerations***

The procedure for this research study began with approval by the institutional review board (IRB) at Wayne State University. Before human subjects approval was obtained I made a clear case of the potential risks and benefits that human subjects might encounter if they chose to participate in this study. This information was also included on the approved informed consent document which all participants signed.

Alexander (2010) states that in order to ethically conduct research among palliative care patients the researcher must pay particular attention to the risk-to-benefit ratio. This is an analysis completed by the researcher and then presented to human subject boards to demonstrate that the benefits of participating in research outweigh the associated risks of harm. A classic definition of *harm* that is frequently used to assess risk is adverse psychological or physical consequences of participation (Cook, 1995). Potential risks of participating in research for palliative care patients are emotional distress such as sadness and/or anxiety (Alexander, 2010; Lintz, Penson, Chabner, Mack & Lynch, 2002), and physical effort which might result in fatigue. There may have been no direct benefit to the participants. However, palliative care research shows benefits to patients in that they value participation in such research as a form of altruism (Gyles, et al., 2007; Hopkinson et al, 2005) by potentially guiding professionals in care for other patients in the future. Participants also report that they feel a sense of engagement by sharing their experiences (Josselson, 2007) and that they appreciate the opportunity to leave a form of legacy for their surviving friends and family (Hunter, 2008).

Particular to this study, the risks of participation included minimal physical (fatigue), psychological (emotional distress from sharing potentially upsetting stories) and social risks (potential breach of confidentiality). In light of these concerns, I paid close attention to the verbal and non-verbal communication of all participants throughout the research process. I am an experienced Registered Nurse with established skills at patient observation and assessment. Participants were informed at the time of

giving consent to participate and before the beginning of the interview, that they had the right to ask me to stop the interview at any point. If a participant had experienced a physical symptom, such as fatigue, I would have paused the interview, as well as stopped the recording and given the participant a rest. If the participant was too fatigued to continue I planned to conclude the interview. If the participant experienced a psychological symptom, such as emotional distress (sadness and/or anxiety) during the interview I would have asked if the participant needed a few minutes to collect themselves, again turning off the tape recorder, and would have continued when the participant was ready. Since the participants were recipients of hospice care they were known to an interdisciplinary team including a chaplain and a social worker that I could have referred them to if needed for emotional distress. I would have stopped audio recording whenever a participant needed a break or rest or at any time any participant requested this. If stopped, the audio recording would not have begun again until the participant gave permission to do so. This only happened on one occasion for the participant who needed to use the restroom. The audio recording was stopped for this patient and was not started again until the participant gave me permission to do so. This was the only one of the above scenarios that occurred. However, I was prepared to address all of them if they had. Safeguards were in place during the duration of this study to protect confidentiality. However, if a breach had occurred I would have notified the IRB immediately and would have proceeded based on their requirements. Potential benefits to this study included an opportunity for participants to share their experiences with hope as lived by a U.S. military Veteran. Insights from this study will help health care professionals better meet the needs of Veterans at the end of life. Furthermore, nursing's knowledge related to hope at the end of life has been expanded and will be used to inform future clinical and educational practice. I worked diligently to minimize potential risks and maximize potential benefits.

### **Recruitment**

Participants of this study were patients of Hospice of Michigan and were cared for by an interdisciplinary hospice team. Participants were referred to me by the Research Coordinator at Hospice of Michigan, who was a part of the agency research team. The research team's manager wrote a letter of support for this study and had copy of the inclusion and exclusion criteria. The Research Coordinator was

trained in human subjects recruitment and research (CITI trained). Once the Research Coordinator completed initial screening of patients for eligibility, she asked potential participants if I could contact them by phone. The Research Coordinator was clear to explain that agreeing to have me contact them in no way obligated them to participate in the research study, nor would it affect the care being given to them by Hospice of Michigan. When potential participants gave verbal consent for my contact, the Research Coordinator gave me the Veteran's name and phone number. When I called potential participants I explained that the research study was aimed at understanding hope at the end of life among U.S. military Veterans. I also explained that if the potential participant was interested in participating in the research study, I would conduct one 60-120 minute interview in their home at a time which was convenient. I explained that the interview would be audio recorded and no compensation for their participation in the study would be given. I also explained that participation in the research study was entirely voluntary and would in no way affect the care received from Hospice of Michigan or Wayne State University. If the potential participant agreed, we set up a date and time for the home visit and I got the address and travel directions.

### **Data Collection**

At the home visits, before the interviews began, I reviewed the informed consent document with potential participants. I offered to read the informed consent to all potential participants. Most of the participants preferred to read the consent themselves, but three of the participants asked me to read the consent to them. The participant and family members who were present were encouraged to ask any questions about the consent. Once all questions had been answered, the participant signed the written consent document. Immediately following the consent process, I administered the Mini-Cog test to the Veteran in order to assess for cognitive impairment. I immediately scored the test to assess whether the participant was currently at a level 2 with a Normal Clock Drawing or greater. This was necessary to complete immediately before the interview began as cognition can change quickly at the end of life. A person who might have been deemed by the research coordinator to have little-to-no cognitive impairment one day, might be cognitively challenged the following day. Once the Mini-Cog test had been completed I

turned the audio recording on and collected demographic information from the Veteran via the Military History Checklist. The information was collected verbally from the Veteran and questions were asked in the order they appeared on the Military History Checklist.

Following the demographic data collection I conducted the research interview. Veterans were asked to respond to the following enabling questions: “What does hope mean to you?” “Tell me what your hopes are.” And “Describe for me what it means to you to have hope at this point in your life.” These questions were meant to open a conversation with the participants and because each individual being interviewed was different, each interview was unique. Phenomenological research is participant driven and the structure of the interview depends entirely on what the participant says. The interview questions were meant to focus the conversation and were followed up with prompts such as “Go on”, “Can you tell me more about that?” “And how did you feel when that occurred?” if the participant needed encouragement or strayed from the research question(s). Participants were allowed to respond to questions for as long as they needed. The duration range for interviews was between 33 and 67 minutes. Once the participant had responded as much as they desired, I asked if there was anything further they wanted to add. The interview was determined to be over when the participant said they had nothing further they wanted to add, I had asked all research questions, or both. I then thanked the participants and terminated the research relationship. No further contact with participants was made.

### **Data Analysis and Interpretation**

Following each interview I transcribed all the audio recordings verbatim. All transcripts were saved in both digital and hard copy formats. I then checked each transcript against the original audio recordings to ensure accuracy in transcription. Once accurate transcription of the data had been verified, I used Giorgi’s (2002) procedural modification for descriptive psychological phenomenological research to begin to analyze and interpret the data. I began this process by dwelling with the data. I read and reread all the texts of the interviews in order to grasp a sense of the whole. I also transferred the typed transcripts into Nvivo 10™ software. Nvivo is a qualitative software program which helps researchers manage data during the analysis process and facilitates data coding.

Once the data was entered into Nvivo I followed Giorgi's procedural steps for data analysis and interpretation. Although the steps are described here in a linear fashion, I engaged in the fluid and the recursive nature of this process. I identified the natural meaning units of the data by intuiting (reading each transcribed interview, line by line), analyzing (sorting what each participant was saying into segments. For example, *mentions God* or *wishes for family*) and describing (the segments). The natural meaning units were coded in Nvivo through the use of *nodes*. Nvivo describes nodes as containers for coding, allowing researchers to gather related information in one place. For instance, if in an interview a participant mentioned God several different times, each instance was placed under the node, *Mentions God*. I identified the natural meaning units (the themes of what each person was saying) of each interview, through the use of nodes in Nvivo. The natural meaning units were then sorted according to themes of commonality and then stated in my own terms. For example, statements made by all participants who mentioned God, church, a higher power, and/or prayer were coded under the node Religion/Spirituality. At this point the data, re-stated in my own words, became known as focal meaning units. These titles are used as headings in the Findings section to follow. I then synthesized similar focal meaning units and formed general structured descriptions. These were the three main themes that emerged from the data and are described in the Findings section. I used the general structured descriptions to answer the research question "What is the meaning of hope at the end of life among U.S. military Veterans?" Finally I synthesized all general structured descriptions and provided a general description of the meaning of the participants' lived experience with the phenomenon.

### **Data Management and Storage**

All data was managed and stored in a confidential manner throughout the study. Participants were identified in the research records by a code name. Any information that could potentially identify the individuals in this study was removed, coded, or changed to mask the details. Signed consent forms, audio recordings, de-identified transcribed texts, and research journals were kept in a secure location when not in use. Consents were not kept in the same location as other research materials. The location for paper records and data storage was a locked file cabinet in my private office. The office was locked when

unoccupied and the file cabinet could only be unlocked by one key, which was in my possession. Computer files were stored on two different computers, both of which were password protected with a password only I knew. I plan to keep the data for one year after the completion of the dissertation defense and then will destroy it securely.

### **Trustworthiness**

Rigor was enhanced in this study by strictly adhering to the steps of trustworthiness. The goal of trustworthiness in this study was to accurately represent the participants' lived experiences of the construct of hope at the end of life. Struebert & Carpenter (2007) describe the four elements of trustworthiness as 1) credibility, 2) confirmability, 3) dependability, and 4) transferability. Credibility was enhanced by the actions I took to "increase the probability that credible findings will be produced" (p. 25). One such action was to triangulate the results by comparing the interview data to my research journal. Creswell (2007) suggests that triangulation of data helps guard against accusations that the findings are unduly biased and/or unsupported. Another way I supported credibility was to immerse myself in the data. Creswell explains that this step helps to ensure that the researcher does not miss any important information. Finally I added credibility to the research study by discussing the research findings with expert researchers and mentors on my dissertation committee. In this study I enhanced credibility by keeping a researcher journal (reflexive journal) to triangulate data, immersing myself in the data and analysis over an extended period of time and discussing coding decisions and findings with my mentors. By completing these steps I increased the probability that what participants' said about their lived experiences of hope at the end of life was accurately represented.

The second criterion of trustworthiness is confirmability. This step involves generating a paper trail for an auditor to follow. In this study I supported confirmability by keeping a field or reflexive journal in which notes about participants, including non-verbal behaviors noted during the interviews, and coding decisions about the data were kept. In this way, I made it easy for another individual, specifically an auditor, to examine the notes and follow the reasoning of the coding decisions.

The third criterion of trustworthiness in qualitative studies is dependability. This criterion can be

demonstrated in a variety of ways, but Creswell (2007) states that it is most frequently achieved through an independent audit which follows an audit trail. In this work, I created a clear paper, audiotaped, and electronic record of every part of the study. This audit trail can be followed by others with expertise in qualitative research. Creswell suggests that an auditor should review original interview transcripts, field journals, data analysis documentation, and all comments from member checking against the text of the dissertation. In this way the research process and decisions are clear and checked by an impartial member outside of the researcher's dissertation committee. For this research study I had a colleague with qualitative research expertise complete an audit of the data. The auditor reviewed the de-identified transcripts, followed all coding decisions and reviewed the natural meaning units from the original data. She agreed with all coding decisions and study findings.

The final criterion of trustworthiness is transferability or fittingness. Struebert & Carpenter (2007) describe this criterion to be the "probability that the findings of the study have meanings to others in similar situations" (p. 26). To ensure transferability it is the researcher's "responsibility to provide the data base that makes transferability judgment possible on the part of potential appliers." (p. 26). I will support transferability by keeping all data descriptions and findings, in a confidential location, for at least one year following the completion of the study. In this way, others might be able to re-examine the data, reinforce or refute my findings. By completing this and all the other aforementioned steps, I enhanced trustworthiness to the degree possible.

This study allowed participants to share their lived experiences with hope and this could have helped them leave a legacy. One of the participants asked for and received a copy of the transcribed interview so that he could share it with his wife and adult children. He said he had not told his children any of the experiences that he had as a Veteran and he thought that they could read his transcribed interview so that they could understand his experiences. Following the conclusion of the interviews a few of the Veterans hugged me and thanked me for completing this research study so others would understand their experiences. One Veteran's sister, who seemed very protective of her brother and remained present during our interview, presented me with flowers at the conclusion of the visit. She hugged me and

tearfully thanked me for doing this research to help nurses care for Veterans. All of these instances supported the value of being able to leave a legacy through participation in the research.

This study adds knowledge to the discipline about the construct of hope at the end of life among U.S. military Veterans. Hope at the end of life among Veterans represented a gap in the literature. This study was rigorous and unique and as such its findings can help direct and customize the care that patients receive from hospice and palliative care agencies.

### **Research Timeline**

I received approval for the research study from Wayne State University's IRB in late December 2012. I am also employed as a faculty member at a university and received required IRB approval from that university in January 2013. I started participant recruitment through Hospice of Michigan in late February of 2013. All data collection activities were completed by the end of May 2013. Data transcription was started immediately following each interview. Data analysis of each interview was started shortly after transcription and comparisons among interviews were made on a continuing basis. For example once interview three was transcribed and analyzed I compared the data of this interview to interview one and interview two. The same process occurred with all seven interviews. Data analysis was completed in late July of 2013.

### **Summary**

While the construct of hope has been studied among people at the end of life, it has not been examined in the unique socially-constructed culture of Veterans. Through this study I uncovered the meaning of hope as it is lived by Veterans who are experiencing end of life. Knowledge gained from this study will serve to inform nurses and other healthcare professionals who are caring for Veterans at the end of life and could potentially be incorporated into care strategies to improve Veteran's quality of life.



## CHAPTER 4 FINDINGS

### Demographics of Sample

A total of seven U.S. military Veterans consented to participate in this study. Saturation of themes was reached after six participants, but a seventh Veteran was interviewed to serve as *a member check*, or a participant to verify the findings of the other participants. Of the seven participants, six were Caucasian and one was an African American. All participants were men between the ages of 50 and 92 years old.

Data collected using the Military History Checklist allowed me to summarize the Veterans' service histories (Table 3). All Veterans served on active duty; two served during World War II (1939-1945), two during the Korean Conflict (1950-1953), two during the Vietnam Conflict (1955-1975) and one served during peacetime immediately prior to Operation Desert Storm (1990-1991). Both Veterans who served during the Vietnam era were exposed to combat and one was held as a prisoner of war (POW) for approximately four years. I assigned all participants pseudonyms, which were men's names chosen at random. The Veterans of WWII were referred to as Hank and Zeke. The Korean Veterans were given the names Darryl and Walt. Gus and Sam were the names given to the Vietnam Veterans. Truman was used to refer to the peacetime Veteran.

The Veterans in this sample served in the Army (n=2), Navy (n=4) and Air Force (n=1). The discharge rank of the Army were E3 (enlisted soldier) and E4 (noncommissioned officer). The discharge rank for the Navy Veterans were E3 (Seaman), two E4s (Petty Officer 3<sup>rd</sup> Class) and E6 (Petty Officer 1<sup>st</sup> Class). The Air Force Veteran was discharged as an O2 (Commissioned Officer). The divisions in which the Veterans served included military police (MP), Infantry, 1<sup>st</sup> Cavalry, Aircraft Maintenance and Mechanic. The duration of service ranged from 18 months to 5 years.

All Veterans in this study reported that at least one other immediate family member had also served in the U.S. military. Two Veterans had one immediately family member who had served. Three Veterans had two or three family members who were also Veterans. The remaining two Veterans had four

or more members of their family who had served in the military. None of the Veterans had family members who were currently serving.

The views of their experiences of being a Veteran of the military varied. Five of the seven Veterans stated that they thought their service was a positive experience. These Veterans served during WWII, Korea, and peacetime. The Korean Veterans and one WWII Veteran said that their military experience allowed them to “travel and see the world” and those opportunities made their service more positive. The two Vietnam Veterans talked of very different experiences. They both used the word “awful” to describe their time in the military. Both also described incidents immediately following their service in which they were involved in physical altercations with others who had either insulted them or their service. One of these Veterans was subsequently diagnosed as having post-traumatic stress disorder (PTSD). The other described in detail his feelings of anger about the service and the events he had witnessed as a POW.

The time the participants had spent in hospice was also recorded. The participants’ length of hospice care ranged from two weeks to one year. It is important to note that this is an atypical stay for hospice patients, as most average just 1 week in hospice services. I did not have access to the participant’s medical record at any time. The participants disclosed the medical diagnoses that had lead to their hospice admissions as part of our conversations. The diagnoses were: Congestive heart failure (CHF) and Lung cancer (CA), n=1; Brain tumor, unspecified type, n=2; Lung CA, n=2; Chronic Obstructive Pulmonary Disease COPD & Lung CA, n=1 and COPD and heart transplant, n=1.

Mini-Cog tests were completed to determine eligibility for all participating Veterans. Five participants scored 3 on the test and were determined to be sufficiently cognitively intact to participate in research. The other two participants scored 2 on the Mini-Cog test, but their Clock Drawing Time (CDT) was normal. These participants were also determined to be cognitively intact and eligible to participate in the research. All Veterans who were assessed were included in the study.

Table 3

*Participant Demographics*

## Era of Service

World War II (1939-1945)	n=2
Korean Conflict (1950-1953)	n=2
Vietnam Conflict (1955-1975)	n=2
Operation Desert Storm (1990-1991)	n=1

## Branch of Service

Army	n=2
Navy	n=4
Air Force	n=1

## Rank at Discharge

Army: E3 (enlisted soldier) and E4 (noncommissioned officer)
Navy: E3 (Seaman), two E4s (Petty Officer 3 <sup>rd</sup> Class) and E6 (Petty Officer 1 <sup>st</sup> Class)
Air Force: O2 (Commissioned Officer).

## Veterans as Immediate Family Members

At least one family member:	n=2
Two to three family members:	n=3
Four or more family members:	n=2

## Diagnoses of Participants

CHF & Lung CA	n=1
Brain tumor, unspecified type	n=2
Lung CA	n=2
COPD & Lung CA	n=1
COPD & heart transplant	n=1

**Findings of Hope**

Using Nvivo 10™ I identified and coded the natural meaning units in each interview. I then sorted these units according to commonality among all participant interviews. I stated these common themes in my own words and created focal meaning units. Once all focal meaning units were identified I synthesized them to create a general structured description which answered the primary research question, “What meaning do U.S. military Veterans experiencing the end of life ascribe to the construct of hope?”

Three overarching focal meaning units emerged in the data. These were 1) The Nature of Hope for Veterans, 2) The Targets of Their Hope and 3) Values Shared by these Veterans. Each focal meaning unit had several subcategories which are discussed here in order to support the general structured description of the meaning(s) that U.S. military Veterans experiencing the end of life ascribe to hope.

### **Nature of Hope for Veterans**

There were several focal meaning units which emerged from the data which described the nature of hope for these Veterans. Among these participants hope was expressed as something which was positive, was related to a point in the future, encompassed a sense of religious and/or spiritual feelings, involved activities which were meaningful and enjoyable to them, and that was shaped by their experiences.

#### **Hope is a positive emotion and helps with coping.**

Each of the participants talked in various ways about hope being an emotion which was positive and/or helped them to cope in some way. For example, Truman was the last Veteran I interviewed and he served as the member check for this study. This meant that the first half of our interview consisted of the same research questions I had asked all the other participants. However, when we had discussed those questions I asked Truman to comment on some of the themes that had started to emerge from other participants' interviews. I noticed that all of the Veterans up to this point had spoken about hope as a positive emotion and/or that hope had helped them to cope in some way with their diagnoses. When I asked Truman if he could comment on this idea, he said that hope for him meant that *my glass is always half full* and that it gave him, *the strength to move forward*. Truman agreed that having hope helped him psychologically and helped his sense of well-being. Other Veterans described hope as a feeling which allowed them to have peace in their current situation. It was clear during these interviews that no matter how the participant expressed the idea, hope was regarded as a positive emotion that helped them remain positive.

#### **Hope is oriented to the future.**

Each of the participants related their hope with the future in a variety of ways. When asked what the word hope meant to him, Hank, a WWII Veteran said it meant *looking into the future while dreaming about the past*. Hank said he looked forward to spending more time with his wife, with whom he still lived. Truman, the peacetime Veteran, said hope meant that he *would have a future* and went on to discuss how he looked forward to enjoying again the activities he once did such as camping, golfing and

flying model airplanes. The future to Truman was an undetermined time from the present. He stated, *I don't know when* (I can do those activities again), *but hopefully in the future*. Interestingly, Truman described hope as being a *light at the end of the tunnel* and that he wanted to *get to that distance* (at the end of the tunnel). From both of the participants I got the sense that hope allowed them to think about a time in the future and look forward to doing things that they enjoyed.

Darryl and Walt, the two Korean Veterans, talked more indirectly about hope having a future orientation. Darryl spoke several times about *hoping to live a little longer* while Walt spoke about hopes that his estranged daughters would eventually treat his wife well. Sam, one of the Vietnam Veterans, talked about hopes that he and his wife could enjoy as much time as possible together and occasionally go on trips to the local casino. Zeke, the oldest of the participants and a WWII Veteran, expressed future orientation of hope when he talked about the vegetable and fruit canning he planned to do later this fall. As I listen to Zeke discuss his plans for canning and observed the excited non-verbal cues he had during the discussion, such as clapping his hands together and smiling brightly, it was obvious that he was wishful that he would live to can his fall harvest. These statements about hopes speak to the individuality of the phenomenon. The futures for which these participants hoped for were all unique.

Gus' perception of hope was quite different from the other participants'. He was a Vietnam Veteran who had experienced the deaths of his parents very early in his life and who had watched several of his fellow servicemen being tortured and killed. In the beginning of the interview, when Gus was asked what hope meant to him, he said, *I don't have any hope*. I restated the question to clarify and Gus still insisted that *I wish, but not any hope*. Further probing led to my understanding that Gus saw hope as being linked with physical mobility and since he was unable to walk he maintained that he did not have hope. Further he said that before he saw his parents and comrades die he had hope, but not after that. Instead he said, *I wish, but not any hope*. After making his distinction between hoping and wishing, Gus talked about his wishes as other participants talked about their hopes and he even sometimes used the word *hope* to describe those wishes. Gus talked about the future as it pertained to his wishes when he said he wished his wife would be taken care of after his death. He also said, *I hope that I don't die and she*

*finds me. I hope somebody else finds me.* When asked why he wanted someone else to find him after he had died he said it would be hard on his wife to find him. Although Gus said he did not have hope, it was clear that he used the word wishes as other participants used the word hope. His wishes for the future seemed also to be helpful to his present circumstances.

### **Hope encompasses religion or spirituality.**

Six of the seven participants spontaneously raised the topics of religion and/or spirituality when they discussed hope. Gus' home had several pictures of religious figures, including Mary and Jesus. When I asked about them, Gus said that those people were important to him and that he really missed going to church. He told me about the pastor at his church and how the pastor often came to visit him. Gus said when the pastor visited him, which was almost every month, he also held church services for the other residents of the apartment complex. The pastor, a gifted musician, also brought his banjo and played gospel music during the services. Gus' eyes were alight when he talked about how this pastor helped him to understand the Gospel. Gus said he wished the pastor could come to visit more often and how happy the visits made him. In between pastoral visits, Gus listened to a music recording the pastor made for him which featured the pastor playing some of Gus' favorite songs.

Darryl did not directly discuss religion or spirituality. However, just after our interview ended, Darryl received a phone call. Darryl had wanted to show me photos of motorcycles he used to own so he had asked me to wait while he took the phone call. During the phone call, Darryl seemed visibly upset. He shook his head several times and became tearful. When the phone call ended Darryl told me that the call was from a long time friend's daughter. The daughter apparently told him that his friend's wife had died in her sleep the previous night. Darryl talked about what a *good gal* the friend's wife had been. He told me how they had worked down the road from each other for most of their careers and how he and the friend's wife would often share a quick lunch together. Darryl shook his head sadly and said, *When it's my time to go, I hope I go just like that* and he snapped his fingers. Darryl then began to reminisce about his own cardiac arrest that happened a few months before our interview. He talked about how he had died, but how it had not been his time to go yet. When Darryl talked about death and his time to die he directed

his conversation towards the ceiling and said *I want to go just like that* and again snapped his fingers. He restated *then wasn't my time to go, but when I do...* As his voice trailed off he looked back at the researcher. The way he stated his conversation was as if he wasn't talking to me, but to someone or something unseen. Although he did not overtly state his belief in a higher power the way that he talked lead me to conclude that he believed in a power higher than himself that was in control of his life.

Zeke, Sam, Truman, and Walt talked about religion in more overt ways. Zeke had several crucifixes in his home and old family Bibles on display. When he talked about hope Zeke started talking about dying. He said, *You know when you get to be my age, the old man upstairs, He makes those decisions. If He wants me tomorrow, I go tomorrow. To me, that don't bother me. No, that don't bother me.* When asked what hope meant to Sam he said, *Hope is, are you speaking of religion hope or...(pause) As far as religion, my perception of that is true. It must be true, you know. That is true.* When asked to elaborate on this further Sam continued, *Well religion has always been important, but as I got older and as I got sick it became more and more important. After I had the first operation, which was a tossup, by the grace of God, you know I made it through. I realized that the doctor was a man, but He was guiding his hands. So, I still say (hope is) about religion, because I had an experience.* Walt shared his hopes about what would happen to him after he died. Walt's first wife had died from cancer and he hoped he would be reunited with her some day. *If I'm lucky maybe I'll go up there with my first wife. Maybe she'll be waiting for me.* After Walt's first wife died he said he had contemplated suicide. *I was a wreck when my wife died. I was a wreck for a good 2 to 3 years. And then I'd think about her and anyway... But boy, those first few months, hmmm (cleared his throat and blinked back tears). I mean I was in bad shape. I mean I was thinking about getting my gun out and ending it. I said if you do that, you're not going up there with her (laughed sadly)*

Because spiritual beliefs had been raised unprompted by all the other participants, I checked with Truman to see if my interpretation of the relationship between hope and belief were in keeping with his perceptions. When asked about religion or spirituality in relationship to his hope he said, *I believe in a higher power.* When asked if he felt this higher power was helping him he said, *"Absolutely...I have*

*come this far and I can go further.* Truman also stated that this higher power was the one who was *giving me strength* so he could get better again.

### **Hope involved meaning and enjoyment.**

All seven participants talked about the importance of enjoyment. Interestingly, they talked about activities they used to enjoy and those they like even now that they are near the ends of their lives. Hank and Darryl had both really enjoyed traveling and camping. Hank used to take camping trips with his wife. He described to me one of his favorite camping spots and said that he really enjoyed traveling. He stated, *we traveled in most of the 48 states.* When I asked him what he enjoyed best about those times with his wife he simply said, *just being there.* After our discussion on past activities of enjoyment I asked Hank what activities he and his wife now enjoyed doing now. Hank became quiet and his answers grew shorter. He said that he did not really have activities he enjoyed doing now.

Darryl said that he also enjoyed camping and traveling with his wife. Until a year ago Darryl and his wife had belonged to a club of motorcycle campers. Darryl described in detail the journeys he and his wife had taken around the country to participate in camping trips. *Yeah, like I say they got them all over the country. I've been to campouts when there were 3 of us sitting by the campfire ... And then I've been to campouts where there were 160 of us.* When Darryl discussed his trips he smiled and laughed frequently. When asked what activities he now enjoyed doing. Darryl became thoughtful and tearful. He said that *I like to go out in the shed or in the workshop and putz around. But all I'm doing now is reading.* He gestured dismissively to a large pile of books beside him and looked brightly, almost longingly, outside to his shed where his motorcycle was parked.

Gus talked about how he had once enjoyed working outside, especially working in construction on bridges. Since he had been using a wheelchair for the past four years, Gus talked about different activities he now enjoyed. These included spending time with a friend who lived in the apartment complex near him and enjoying the equipment that assisted their mobility . *I have an electric car (points to his wheelchair down the hall)... And I get in there and ride around. And (friend's name) upstairs he brings me a Pepsi....he goes out with me when its warm...He's got this little cart that we go around on.*



*It's got these big wheels on the back and we go ride around on it sometimes. It's like a rocket sometimes.*

Sam spoke about activities he used to enjoy doing, such as going to a casino and to church with his wife. He told me he was less able to do those things now and preferred to watch church on TV because it was too hard for him to leave the house.

Zeke shared his love for photography. While he served in the military he photographed the base where he was stationed and the actors and actresses that performed during the USO shows during his time there. He showed me several photo albums of his photography, but said he did not take photos much anymore. He also talked about the canning and beer brewing that he used to do. When asked what activities he enjoyed doing now he said he still canned, but did not make beer as much anymore. He also gestured dismissively towards his TV and a large stack of books that sat beside his chair (similar to Darryl's pile), but he did not seem to want to discuss them. It was obvious during the interview with Zeke that he enjoyed interacting with people and that he missed many of those interactions now that he was unable to leave his home.

Finally, Walt talked about the dancing he and his wife had done. He said, *my wife and I used to dance a lot, but now we don't dance. So all we do is go to the restaurants.* He also talked a lot about a cottage he owned on a nearby lake and how he had loved spending time on the lake riding *Ski Doos* and driving his pontoon boat. Walt said he had not been to his cottage in several years because he had not been able to negotiate the stairs in and around the house. Walt said he now spent his time watching Fox News and *putzing and smoking in the workshop* in his garage.

In this study participants described the meaning and enjoyment they had in their lives as it related to hope. However, they also talked about how the meaning they had through activities of enjoyment had changed since their terminal diagnoses. Some, like Darryl mourned the loss of previous activities, while other seemed to have made peace with these changes.

### **Hope is shaped by your experiences.**

A finding that pertained to two of the Veterans, but I believed to be significant, was an idea that Sam and Gus both expressed. These participants were the combat Vietnam Veterans and they had

different experiences in terms of their service than did the other participants. Sam served in a combat forward area for *11 months and 20 some days*. Sam relayed to me that, during that time he had experiences with death. He had seen members of his unit die in front of him and recalled one instance in particular where he had killed another person. *My worst experience was...uh, I had to... I had to... uh shoot a kid. That was..., that, that was my...that that was my worst experience. I dreamed about it for a long time.... Uh and uh.... I was so upset I ended up going to the hospital.* Later in the interview Sam said, *well this is, I mean, your experiences, you know your experiences shape your hopes. I mean, that's the only way I know. The only way I can see. My hopes, I have to some idea in order to hope.* Gus indirectly shared similar thoughts. He was the Vietnam Veteran who had been captured and held as a prisoner of war for four years. During that time he had been tortured and had watched members of his unit go through extreme suffering and death. When asked about his experiences in Vietnam he said, *That didn't bother me as bad as people dying. I mean they came and cut their legs off, cut their arms off....Torture. And I got so strong I could just take their (the enemy's) head and bust it, so I did it when they came, when they came to get me. Then I paid for it.* After this statement Gus immediately changed the topic to the Vietnam Wall Memorial, closing further discussion about this. These were not the only deaths Gus had experienced. He had been with both of his parents when they had died. These deaths, just a few months apart, occurred just prior to Gus entering the service. Then, immediately following his discharge, he was mugged by five assailants and killed one of them in self- defense. Gus' made this statement that showed how his hopes were shaped by his *experiences, You know when my mom and dad was living, I had a little bit of hope. That it (life) would be good for them.* Gus' perceptions of hope had been changed after witnessing many deaths and traumas in his life. These thoughts echoed Sam's summary that one's experiences shape one's hopes.

The nature of hope was expressed in unique ways by participants. However, it is important to note that common ideas were present in the majority of the Veterans' interviews. These participants described the nature of their hope as being emotionally positive, future oriented, related to their religion

or spirituality, associated with meaning and enjoyment, and shaped by life experiences. Hope was also distinguished from wishes in some cases.

### **Target of Hopes**

The seven Veterans who were interviewed expressed several targets for hopes. These included hopes for themselves and hopes for others. Veterans hoped not to suffer while dying and to leave a meaningful legacy, which was often expressed through their military service to the country. Those Veterans with spouses hoped to provide protection for their survivors.

### **Hope not to suffer.**

When discussing their hopes for themselves, six of the seven participants said they hoped not to suffer during their terminal illness. Darryl and Walt expressed the hope not to suffer in pain. Walt said, *As long as I don't start hurting... because I'm a big coward when I hurt (laughs). But I'm not hurting now. My shoulder gives me a problem, but that's arthritis and I get a little pain where I have the surgery (points to ribs)...Yeah, mostly that's why I take pain pills, not from the cancer, but from my shoulder. When they operated they must have pulled this arm, way back, you know. This arm here's my bad one and ever since I had the operation it hurts twice as bad as it did before. If that's the only pain I get, I'm ok.* Darryl expressed this hope when he said, *I don't wanna, you know, I don't really want to get to the point where I am suffering all the time.*

Zeke also talked about suffering as it related to pain. He told me he took the pain medications he had been prescribed for metastatic cancer pain and as long as he did, *there's nothing wrong with me.* It is important to note that Zeke seemed very open during the interview and was willing to share his thoughts and feelings with me. But I also got the impression that he did not want to complain. At times his nonverbal communication suggested that he wanted to continue talking about things which made him sad, such as the loss of his wife, but when I used probing questions to explore those topics he would smile, shake his head and change the subject. I wonder if Zeke was not entirely comfortable disclosing his feelings to me as a young female researcher, or that he was a member of a generation where complaining was not a tolerated social norm for men.

Gus and Sam also expressed their own hopes to avoid suffering. Gus said he did not wish to prolong his time in this life. He was the Veteran that said he did not have hope and that he did not have any quality of life. Gus said, *You see these legs won't go any more. Well I wish that there was... I wish that they would stop. That they (referring to his legs) would stop or I would stop.* It was unclear what Gus meant by wishing his legs to stop. However, it was clear that Gus did not want to live a life where he was unable to walk. Sam expressed his hope not to suffer when he said; *I have a thing about pain. When I expire, I don't want, I don't want pain. I'd rather, they used to have a song: 'I wanna die easy' You know, I guess that symbolizes how I feel about pain.*

Truman, the peacetime Veteran who was interviewed last, stated that his immobility was making him suffer. Several times he referred to getting back to the *Normal me, not me laid out like this.* Further he said he worked hard to do hand and leg exercises that he had devised in order to regain strength in the limbs affected by cancer. I noted that Truman had been in hospice just a few weeks when we conducted our interview whereas others had been enrolled for up to a full year. He and his family seemed convinced that despite his medical diagnosis he was going to recover. His vision of and hope for the future did not include suffering and so he worked hard every day to counteract his current state and remain optimistic. Hoping for a cure can be common in people who have been newly diagnosed with terminal illnesses. Hospice providers often help the patient and family transition from hoping for a cure to hoping for peace and comfort. Truman's hope to get back to normal could be related to the fact that his terminal diagnosis was so new to him.

### **Hope for a legacy.**

When discussing hope everyone in the study talked about wanting to be recognized or remembered for their service to their country. Each one had a uniquely perspective on this, but all of the Veterans seemed to want to believe that their service to their county matter. Truman told me that he was discharged from the military just prior to Operation Desert Storm. He talked about how a lot of friends from his unit had died and how he was glad not to have served during the war. But he also said he was proud of their service and that he hoped people had seen him, as an officer, as an important part of that

service. Truman's family also profusely thanked me as I left and told me this type of research was important to honor the service Veterans had given to their country.

Gus and Sam also spoke about how they hoped that service to their country mattered. Sam had recently been honored by a nearby Veterans' organization. The local paper had covered the event, and Sam and his wife eagerly shared the story with me. Sam was also working on his legacy by writing poetry about his experiences in Vietnam. One stanza of the poem he chose to share with me seemed to capture his experience eloquently:

*A land of love and broken dreams*

*A land of hills, valleys and streams*

*A land of confusion, a land of doubt*

*A land of rebellious cries and shouts*

*For if you gave a damn and most didn't care*

*Who governs this land of sorrow and despair?*

Although Sam had a difficult time with PTSD after his discharge it was obvious that his military service mattered greatly to him and he hoped that others would value it as well. Gus spoke in detail about a particular time right after he left the service. He spent a great amount of time recovering from physical injuries at Walter Reed Army Medical Center in Bethesda, MD. He said one of the nurses, who was supposed to be caring for him, called him a *baby killer*. Gus was very proud of his service and the comment so infuriated him that he punched the nurse in the face. Gus also told me *I got my Purple Heart and my picture on the wall* and that recognition by his government meant a lot to him. I did not see the picture he was referring to and he did not offer to show me his Purple Heart medal, which is a military merit award given to those wounded in action. However, I did notice that he sat up straighter when he talked about receiving the Purple Heart. It was my impression that he was proud to have this distinction of his service.

Walt and Darryl also expressed a hope that service to their country mattered. Darryl said, *I understand now that the world is actually a better place, because I've been here and I was there and I*

*know what is going on. It is hard to understand why we are over there in Afghanistan, fighting them darn religious wars....You see on TV these people come back with legs missing and stuff and nobody cares (tearful) and that hurts.* It was obvious me that he wanted his service and all Veteran sacrifices to matter. Walt was less direct about expressing his hope that his military duty mattered. He said that his time in the Navy was positive overall and that he saw a lot of the world. Walt talked about the fact that he had bought a burial plot in the Veteran section of the local cemetery. He said, *When I first came out of the service... when we were first married, some guy came along and was selling in the Veteran's section there. I was an only child so I got my mother and dad and me and (first wife) plus an extra 5... So I'm gonna be buried next to her (first wife)...* Choosing the Veteran section of the cemetery as a final resting place for his body indicated to me that he wanted to be remembered for service to his country.

Hank and Zeke also shared their hopes about wanting to have their service acknowledged. Hank had just been recognized by a local organization and proudly showed me the award that was prominently displayed in his home. Zeke showed me several old photograph albums full of pictures that he took during his service and told me many stories about his time in the military. When we ended our interview session, Zeke shook my hand and said, *thank you for listening to my stories.*

### **Hope for survivors.**

Among the seven participants, five were currently married. Of the other two participants one had been divorced and one widowed and, neither had remarried. Interesting to note was the divorce pattern among this small group of Veterans. All but two of the participants had been divorced (71.5%). Their current spouses were second marriages and one Veteran was in his third marriage.

Six of the seven participants expressed hopes for their families after they died. Hank, Sam, Walt and Gus defined family narrowly. To these participants their current spouse was the only person in their family they had hopes for after their deaths. Some hoped for more time with their spouses, while others hoped to provide protection for their spouses after they died. Hank expressed a desire to spend more time with his wife while he was still able. Sam also spoke of his hopes for his wife. *Oh, you... there are so many things that I didn't do, that at this stage of the game (laughs). I'm just gonna enjoy my wife. And we*

*do enjoy each other, even more so now, you know.* One of the main things they used to do together as a couple was going to a nearby casino and Sam hoped that he and his wife could do that together again soon. Walt and Gus expressed hopes to provide protection to their spouses after they died. Walt talked a great deal about making sure his estate was in order before he died so that his wife was settled. He stated, *Oh yeah, yeah I want her to be well taken care of. That's why I made a new trust out. I knew my kids weren't going to take care of her.* Walt also talked a great deal about an argument he had with his daughters over his estate and how by intervening now he was hoping to take care of his wife. *But (a family cottage) would be in my name until my wife and I died and they (daughters from a previous marriage) would get it, but they're not going for it. They don't trust us, because they figure if I die, (current wife) will sell it. (Current wife) don't want no part of it, she just wants to get rid of it. So I'm thinking very seriously of selling it.* Gus spoke about a similar idea. He was very proud of what a strong relationship he and his wife had. She had helped him readjust after his divorce and his military service and he had helped her to stop drinking. He hoped for his wife not to find him after he died because he felt it would be too hard on her. It was clear from their statements that these Veterans had hopes for their families, but the most important relationship to the majority of them was the one they had with their current wives.

Six of the seven participants had adult children. Most reported not having close relationships with their children. Gus said he had not spoken to his daughters in more than a decade and Walt had stopped speaking to his adult daughters nearly six months prior to our interview due to a disagreement about his estate. Hank, said that he does not see his living child any longer because the son lives in another state. He does not speak to the son because he does not like to talk on the phone. Sam mentioned that he had adult children, but did not talk about any hopes he had for them. Only Zeke and Darryl mentioned hopes they had for their children. Zeke was widowed several years ago. He and his late wife had two children together and had served as local foster parents. Zeke and his siblings had been put in an orphanage during the Great Depression because his family could not afford to feed all of their children. Zeke told me a story about trying to keep all of his siblings together until his mother and father could afford to bring them

home again. The two years that Zeke had spent in the orphanage seemed to have defined his sense of family. Family to him included his deceased wife, their children, grandchildren and great-grandchildren, his foster children, and his siblings one of whom was still living. Zeke said his hopes for his family were *just to have a happy family and I don't want no hard feelings. We never argue. I mean for fun we do, you can ask any of them. We never fight, never did.* Zeke further showed evidence of hopes for his family when he showed me the genealogical work he had done. He had traced his lineage back more than four centuries. He organized his work on large poster boards and kept a binder full of documents that he planned to leave to his family when he died. Darryl said his biggest hopes for his family were related to their health. He stated, *You gotta understand the (surname) family...my dad died at 55, my younger brother when he was 49, my youngest brother has already had 3 (gestured to his chest) put in his heart. So the whole (surname) family has heart problems. That's the only thing that I tell them. Take care of that heart.*

The targets of hope for these Veterans were for themselves and others. For themselves, Veterans hoped not to suffer and to leave a meaningful legacy through their military service. The married Veterans all spoke of hopes to either spend more time with their wives or to provide protection for them after their deaths. Veterans who maintained relationships with their adult children hoped for their well being.

### **Shared Values**

There were three common values reflected in the Veterans' narratives. These related to 1) maintaining control, 2) avoiding alcohol, and 3) strong work ethics. These values, although not shared by every participant, seemed important to some in shaping their hopes.

### **Maintaining control.**

Most of the Veterans talked about control when discussing hopes. Truman tried to control his situation by completing hand and leg exercises that he had devised in the hopes of becoming stronger. When asked about these exercises he said, *in the military you always get the job done. Period, stop. I want to get the job done.* He saw his exercises as beneficial to his strength and influenced his perception of hope. The lack of control Gus had over his mobility seemed to frustrate him. This was evidenced



through his statement, *I wish I would go ahead and die*, which was immediately followed by his statement, *I wish, but hope I don't have*.

Walt expressed ways in which control was important to him when he discussed his estranged daughters and the situation with their family cottage. Walt's ability to control the situation and determine the outcome was extremely important to him. Darryl also spoke of control when he said, *You know, the doctors already told me, but you're still gonna be hoping that your still gonna live for a little longer*. This desire related to control when he spoke about his friend's wife who had just died. He talked about when it was his time that he wanted to die a very sudden death. Zeke expressed a desire for control and actions that reflected his values when he told me he was writing his own obituary so that his family would *get it right*. While each Veteran had a unique ways of expressing this theme, a desire for maintaining control, even in the midst of an uncontrollable situation, seemed to be important for most of the Veterans in this study.

#### **To avoid alcohol.**

None of the participants of this study were members of Veteran social organizations such as Veterans of Foreign Wars (VFW) or the American Legion. When asked why they chose not to participate in these social organizations, most of them said it was because they did not like the drinking that took place at the organization-sponsored events. Darryl, who had just been honored by a local Veteran organization, said that although he went to the ceremony held in his honor and he really appreciated it, he was not inclined to join them on other occasions. When asked why not, he said he did not drink alcohol and that they do a lot of drinking at his local branch. Walt said, *I dropped out of American Legion and VFW... all those places where you go. The American Legion here (in hometown) is the worst place, God almighty. You know in Florida they have those big places and they have dances and dinners. This one here, don't have anything, nothing!* (laughs)...*Well they all had bars, but neither one of us drink. I've got liquor in my cabinet that must be 40 years old, hasn't been open yet*. Gus also belonged to Veteran social organizations in several other states, but found his local chapters had too much drinking and too few activities. Gus and his wife stopped drinking years ago. He said, *I quit all that running around and*

*fighting. She was drinking all the time and I changed that about her.* Sam simply stated that he and his wife do not drink for personal reasons and found that there was too much drinking at their local Veteran organization chapters so they chose not to attend. I did not ask if any of these men had alcoholism issues in the past, but not drinking or wanting to be around those who did was a reoccurring theme for these participants.

### **Strong work ethic.**

A strong work ethic was also strongly valued. Zeke expressed the value of a strong work ethic when he talked about keeping his mind and body active by writing, canning, and completing puzzles. He did not enjoy sitting around *doing nothing* and watching *that idiot box* as he called television. Walt evidenced that he valued a strong work ethic when he spoke admiringly about his wife and the work she did around the house. *I can't do anything physical at all. But other than that I'm doing ok. (Wife) does everything for me. Everything, she shovels the snow, she blows the snow, she cuts the grass, takes care of the house and cooks... Oh, I don't know what I would do without her.* Darryl had fallen recently while trying to carry groceries from the car to the house. Darryl described how he had worked hard his whole life and how slowing down now that he was sick had been really hard for him, *the last few years, I've always been active all my life you know.* When Gus described his wife he said, *She is just like her dad was, 86 and he worked every day...She's just like her dad. He bought up behind their land and he bought it all and made roads through it. The roads went all through it. My mother-in-law, was all crippled. She was in a bed for a long time. She was all crippled from here to here, but my father-in-law, nah.* Sam related a story me about being able to depend on the other members of his unit. He was proud of them because, *when it comes down to taking care of business I'd rather be with (them).* Finally Truman confirmed this theme. He said that in the military you *get the job done.*

The general structured description of the meaning U.S. military Veterans experiencing the end of life ascribe to hope is that hope exists, is a positive emotion which helps them with coping, is future oriented, involves the human spirit, is linked to meaning and enjoyment of life's activities, and is shaped by life's experiences. Veterans in this study hoped not to suffer as they died and to leave a legacy related

to their military service. Those with spouses either hoped to spend more time with them or to offer them protection after they had died. Further, the majority of the Veterans valued maintaining a sense of control, avoiding alcohol, and strong work ethics. All of these findings suggest that while many of the ways Veterans experience hope at the end of life is typical of persons with terminal illness, there are some themes unique to this cultural group.

## CHAPTER 5 DISCUSSION

The aim of this study was to explore and understand the lived experiences of hope among U.S. military Veterans at the end of life. I used a phenomenological method to achieve this aim. I discovered the nature of hope among these Veterans. I also discovered that the participants had common hopes and values. In this chapter I will discuss the findings more fully in the context of the available literature and suggest implications for education, practice and research.

### Discussion of Findings

#### The nature of hope.

The nature of hope expressed by these participants was that the phenomenon was positive, was related to a point in the future, encompassed a sense of religious and/or spiritual feelings, involved activities which were meaningful and enjoyable to them, and was shaped by their experiences. Hope as a positive emotion or one which helps people cope with their lives has been identified in the literature. Several studies with non-veterans have examined hope and found the phenomenon to reflect a similar idea (Duggelby, Williams, Wright, & Bollinger, 2009; Ferrell & Coyle, 2006; Frankl, 1984; Lin, 2008). In these research studies, participants had hope in the face of a terminal illness which allowed them to maintain a sense of positivity even while facing their own imminent mortality. Hope reflecting an orientation to the future is also common in non-veteran literature. Prior studies with populations of people who are well (Buckley & Herth, 2004; Cutcliffe & Herth, 1995; Duggelby, 2001; Elliott & Olver, 2009; Herth, 1992; Johnson, 2007; Miller, 2007; Parse, 1999; Parse, 2007; Reder & Serwint, 2009) and those who are experiencing the end of life (Duggelby & Wright, 2009) validate this research finding. Current literature also supports the nature of hope encompassing religiosity and/or spirituality for those who are terminally ill (Duggelby & Wright, 2009; Herth, 1992), and those who are well (Basset, Lloyd, & Tse, 2008; Buckley & Herth, 2004; Duggelby, 2001; Johnson, 2007; Neederman et al., 2010; Reder & Serwint, 2009). Also supported in the current body of literature is hope being affected through facilitating individual activities of enjoyment (Jonsdottir, Jonsdottir, Steingrimsdottir & Tryggvadottir, 2001; Kennett, 2000; Klager, Duckett, Sandler & Moskowitz, 2008;). The nature of hope that two of the combat

Veterans expressed was their present hope was shaped by past experiences. These Veterans were specifically talking about the traumatic events and deaths they witnessed during their military service. A large amount of current literature has been dedicated to the study of traumatic events during military service and current psychological health. These traumatic events often include witnessing the deaths of fellow service members (Currier & Holland, 2012). Only one study could be found in which terminally ill Veterans were asked about their combat experiences and how this affected their hope later in life. Hilton (1997) studied Veterans of WWII 50 years after their service. Hilton found that the traumatic events her participants witnessed and endured affected the way they saw their present world. In this study only combat Veterans mentioned this idea. Yet the traumatic events of their past, some as long as 40 years ago, were still significant enough in their lives for them to state their present hopes were profoundly shaped because of them. Further research should be conducted in this area to substantiate this finding.

Another important idea to consider when trying to understand how the participants of this study envisioned hope at the end of their lives by recognizing their initial introduction to end of life. At a young age the majority of these men were exposed to death not through books, media or by illnesses, but through war. Through their military service these participants were forced to confront death during a time at which their psychosocial abilities to handle it might not have been fully developed. According to Erik Erikson (1959), young adults, those who are approximately 18-35 years old, are entering a stage in their lives when they are forming connections by relationships. Erikson states the typical relationships of this age of person are marriages and birth of children. When these participants were of an age when they should have been developing these relationships, they were serving in combat forward areas, being held captives in prisoner of war camps or actively killing enemy soldiers. These firsthand accounts of death at such a young age cannot be ignored when considering their perceptions of any phenomena at the end of their lives.

### **The targets of hope for Veterans.**

The seven Veterans who were interviewed expressed several targets for hopes. These included hopes for themselves and hopes for others. Veterans hoped not to suffer while dying and to leave a

meaningful legacy, which was often expressed through their military service to the country. A hope or a desire not to suffer at the end of life has been sustained in a vast amount of literature. Researchers have examined the concept of suffering at the end of life most commonly as it relates to pain and symptom management (Axelson, Randers, Lundh, Jacobson & King, 2012). The participants of this study did talk about the desire not to be in pain. It was my impression that the expression of this hope by the two combat Veterans was related to their witnessing of traumatic events. One of these Veterans talked about killing a child during his service and how that event still haunted him. The other Veteran, who was a POW for four years, had seen members of his unit being tortured and killed. He had also, at a young age, witnessed the death of his parents. It was obvious throughout the interview that these events still affected his sense of hope. While the hope not to suffer as it relates to experienced military trauma has been sustained in the literature (Hassija, 2012; Roberston, 2008) the amount of research on this topic is limited. This finding needs further investigation.

Hopes that these participants wished to leave a legacy through their past military service to their country is not uncommon among Veterans. Honoring the service to our national military Veterans is a value in our country. As a nation we honor our Veterans with countless parades, ceremonies and memorials and even have a national holiday (Memorial Day) to remember the many sacrifices Veterans make. We have developed the U.S. Department of Veteran Affairs which provides healthcare and benefits to our Veterans while honoring them with awards and other recognitions. The National Hospice and Palliative Care Organization instituted the *We Honor Veterans* program to identify and appropriately care for those who are receiving hospice and palliative care services (Wehonorveterans.org). First Lady Michelle Obama and Dr. Jill Biden have started the *Joining Forces Initiative* which is working with community partners to help Veterans in all areas of their lives (whitehouse.gov/joiningforces). It seems logical with the emphasis the nation has placed on honoring Veterans that that participants would want to be remembered for their service to their country.

The ways in which our nation honors individual Veterans is limited. Local Veteran organizations, such as the American Legion or the Veterans of Foreign Wars can honor their members and/or

community Veterans with plaques or ceremonies. Several of the participants of this study had had experiences with this type of recognition. Also, when a Veteran dies the VA will provide the family, upon request, with a burial flag to drape the casket or accompany the urn. The flag is given to the next-of-kin and meant to be kept as a keepsake after the funeral. If the family lives near a VA National Cemetery with the Avenue of Flags, they can donate the burial flag of their loved one to be flown on national holidays ([http://www.cem.va.gov/burial\\_benefits/burial\\_flags.asp](http://www.cem.va.gov/burial_benefits/burial_flags.asp)). These types of services are ways in which people can acknowledge and remember an individual's service. None of the Veterans talked about the posthumous presentation of the flag to their family so I am not sure if they knew about this service so they could help create a legacy through their service.

All of the Veterans in this study demonstrated pride in their service. They had photos of themselves in uniform displayed in their homes, car licenses plates identifying them as Veterans, and medals and commendations prominently displayed in their homes. I saw that they all strongly identified with their status as a Veteran. It seems logical that they would want their service to be appreciated and remembered. While a hope to leave a legacy is common in the end-of-life literature, the hope to create a legacy through military service has not been identified in the nursing literature specific to the lived experiences of hope. However, a desire to have military service remembered has been shown for those Veterans who strongly identify with their Veteran statues ([aacn.nche.edu/el nec/about/el nec-for-veterans](http://aacn.nche.edu/el nec/about/el nec-for-veterans)).

#### **The targets of hopes for others.**

Those Veterans with spouses hoped to provide protection for their survivors. Having hopes for one's family at the end of life is not uncommon. Several nursing researchers have discussed this idea (Duggleby & Wright, 2009; Elliot & Olver, 2009; Johnson, 2007; Miller, 2007). However, what is unique to this study was the idea that it was their current spouses rather than their adult children or grandchildren that these Veterans had hopes for. This could be due to the high divorce rate and serial marriages in this particular population. Pollard, Karney & Loughran (2008) completed longitudinal studies on Veterans and calculated their divorce rates. Pollard et al. found that the divorce rate among Veterans is significantly higher when compared with matched non-veteran civilians. The high divorce rates could be a clue into

this unique finding of hope in this study, however its implications are not yet clear.

### **Values shared by Veterans**

There were three common values reflected in these Veterans' narratives. These related to maintaining control, a desire not to drink, and strong work ethics. These values, although not shared by every participant, seemed important in shaping the hopes of those who did mention them.

The desire to for Veterans to exercise control, especially at the end of life has been noted in previous research (Fischer, et al, 2007; Rodriguez & Young, 2006). The Veterans in this study spoke about control in a variety of ways from estate planning to obituary writing. This theme was extremely important to these participants and could be related to the independent and hard working attitude they all seemed to possess.

Without being prompted the majority of the Veterans said they did not belong to a Veteran social organization because of the amount of drinking that occurred at these organizations. Rabb & Ban (2010) and Hobbs (2008) found that Veterans who strongly identified with their Veteran status were more likely to be members of Veteran social organizations. For the participants of this study that was not true. None of them were current members of Veteran social organizations, although a few had been members in the past. The main reasons they cited for not being current members of these organizations were lack of social activities and excessive alcohol consumption by the members. Although these findings could not be substantiated in the research literature I did discover from examining Veteran blogs (<http://veteransguide.blogspot.com/2011/08/vfw-sometimes-problem-for-certain.html>) and news releases ([www.topix.com/forum/city/pepperell-ma/T4060E73SJN0S5SRH](http://www.topix.com/forum/city/pepperell-ma/T4060E73SJN0S5SRH)) that the overconsumption of alcohol at these organizations often occurs. Although the participants of this study identified themselves as Veterans they were not members of Veteran social organizations. This finding suggests that Rabb & Ban's (2010) and Hobbs' (2008) definitions of Veteran identification might need further investigation.

It is not clear whether the value of a strong work ethic is due to the fact that all of the participants are Veterans, their ages and life experiences, or a combination of all factors. Earle, Myrick & Young (2011) noticed the value preference for a strong work ethic in their systematic review of literature about



generational cohorts. Earle et al. suggested that people born before 1960 place more value on a strong work ethic than do people in younger generations. The participants in this study were born between the years of 1921 & 1963. These generational considerations could be an indication for the emphasis the participants placed on the value for a strong work ethic. Alternately, Petrovich (2012) states that the basic outcome of military training is to produce a strong and efficient soldier who is “tough, unflappable and steady even in the face of life-threatening danger” (p.870). Petrovich suggests this attitude, instilled in military members through training and service, does not leave the member once discharged. The research finding of valuing a strong work ethic could also be related to the participants’ military service. It is unclear if the generational affiliation or the Veteran status of the participants or a combination of both factors influenced their values. However, what is clear is that the theme of valuing a strong work ethic was evident in the majority of the participant interviews.

The nature of participants’ hopes echoed what was reported in the literature, but with some differences, specifically the idea that past combat experiences shaped present hopes. The targets of their hopes included themselves and their families. Hopes for themselves, such as not to be in pain and to leave a meaningful legacy, were previously identified in the literature. However, the meaning these participants attributed to family was unique. Those Veterans who were married identified their family as their current spouses only; most of the Veterans who had children and grandchildren did not say they had hopes for them. The values that these participants shared related to maintaining control, a desire not to participate in Veteran social organizations to avoid alcohol, and a strong work ethic. These findings could be found in the literature, but there amount of research related to these topics was limited. Veterans, who had combat related service, believed their current hopes were influenced by past traumatic experiences.

### **Implications**

The purpose of this study was to discover the meaning of hope at the end of life among U.S. military Veterans. The information gained from this study adds to nursing’s knowledge about the construct of hope and the unique and common perspectives of Veterans. The findings add to Morse et al.’s (1996) criteria of construct analysis. The findings help provide definitions and characteristics (nature

of hopes) for hope. Furthermore, the findings from this study have the potential to help nurses who are caring for Veterans at the end of life promote psychological quality of life. U.S. military Veterans, as a socially-constructed culture, have been given little attention. Considering Veterans as a distinct culture is a relatively new idea, in fact, no research studies could be found that addressed hope among U.S. military Veterans at the end of life. This study fills a gap in nursing's knowledge of the phenomenon of hope. This study also fulfills an ethical obligation of nursing to add knowledge to an understudied area as described by the American Nurses Association.

### **Education**

It may be too early to posit education implications from the findings of this study. However, from the thorough literature search I conducted I can safely conclude that prelicensure undergraduate nursing students might not receive enough end-of-life content in their education. Findings from this study could help to contribute to undergraduate nursing students' education. The Joining Forces Initiative, which was started to address the needs of past and present military service members, has three foci 1) employment, 2) wellness and 3) education ([whitehouse.gov/joiningforces](http://whitehouse.gov/joiningforces)). Joining Forces has partnered with the American Association of Colleges of Nursing to engage undergraduate nursing schools nationwide to support the education focus. The goal of this partnership is to increase Veteran content in undergraduate nursing curriculum. Presently more than 500 colleges of nursing have pledged their support to this initiative. Knowledge from this study could be useful to incorporate Veteran content in undergraduate nursing curricula. Meaningful ways of doing so could include simulations and interactive case studies (Harmer & Huffman, 2012) in which Veteran patients are experiencing the end of life and undergraduate nursing students are challenged to care for them in a culturally-congruent manner.

### **Practice**

Practice standards are likely not going to change based on the findings of this study. However, it is estimated that there are 22.2 million Veterans who receive care in our country and only 4% die in VA facilities ([aacn.nche.edu/elnc/about/elnc-for-veterans](http://aacn.nche.edu/elnc/about/elnc-for-veterans)). All nurses, not just those who work in VA

facilities must be trained in the unique care needs of Veterans. More support from research is needed to explore the care needs, specifically those at the end of life among this culture.

### **Research**

The findings from this study suggest that research which examines the lived experiences, specifically hope, at the end of life among Veterans is limited. Advances in healthcare are increasing the length of life for all people nationwide. Veterans' lengths of life are likely to increase and the illnesses they suffer from will become increasingly complex. Research dedicated to understanding their lived experiences is essential to nursing education and practice.

### **Strengths and Limitations**

Strengths of this study included the sample size and the sampling method. Seven Veterans were consented for this study, with one participant who served as both a participant and a member check. In qualitative research a sample of seven participants, who serve as key informants is considered adequate to describe the essence of an experience (Morse, 1991). This study used a purposive sample method. In qualitative studies participants are asked to participate specifically because they have knowledge of the phenomenon. For this study, the researcher used a purposive sample because it was the best method to uncover the meaning of the phenomenon for the population. Other methods of sampling were not appropriate for this type of research. An additional strength of this study was that allowed it participants, by telling their experiences with the construct of hope, to leave an additional legacy. The idea of leaving a legacy is extremely important at the end of life and is often done through sharing life experiences.

One limitation to this study was that participants were recruited from only one agency, Hospice of Michigan. When trying to understand a universal phenomenon, such as hope, studies should include several different facilities or agencies in multiple locations. However, since this phenomenon had not yet been studied among this cultural group the one agency approach was an appropriate starting point. I plan to expand this study to other facilities, across the region, and eventually nationwide as part of my emerging program of research.

Another related limitation stems from the fact that participants in this study were recruited from a community hospice program rather than from the population of U.S. military Veterans who receive their end-of-life care within the VA system. Veterans in VA care might have felt differently about hope at the end of life. Although I attempted to pursue this approach, it was not possible to recruit participants receiving care at the local VA. In the future I would like to partner with the local VA facility to replicate and extend this study in that population.

A third limitation is that data could only be collected from each participant during one interview of about one hour. Although I am confident that I identified and spoke to an appropriate number of Veterans with the specific experiences I was investigating, it might have enhanced credibility to have more extensive interactions with the participating Veterans. Unfortunately, this is a common problem in research with people near the end of life (Pessin et. Al, 2008). Timing of research participation is frequently difficult due to sometimes rapidly changing mental capacity, fatigue as the serious illness progresses, and family caregiver distress as death approaches. I worked diligently to minimize the limitations in my study. The ways I did this included having the hospice program identify potential participants that were likely to be able to engage in the research, reassessment of mental capacity just prior to the interviews, and the decision to limit interaction with each participant in favor of exploring the phenomena with a larger number of Veterans.

### **Future Research**

I plan to expand this study into a program of research with U.S. military Veterans. I was intrigued to discover that although all participants ascribed similar meanings to hope at the end of life and hoped for similar things, there were unique ways in which they expressed this related to their era of service. For example, the WWII Veterans' war experiences and homecomings from their service were very different than the Vietnam Veterans'. In a future study I would be interested in recruiting several Veterans from these two eras to compare their experiences with hope at the end of life. Further, I would like to examine the experience of hope at the end of life as it is experienced specifically by combat Veterans, particularly those who have been diagnosed with PTSD.

This study begins to answer the research question what meaning U.S. military Veterans ascribe to hope at the end of life. This study has addressed a gap in nursing's knowledge by revealing part of this previously ignored socially constructed group's perspective. This study is a small first step in understanding how hope at the end of life is experienced by U.S. military Veterans, but an important one.

**APPENDIX A****INFORMED CONSENT****Behavioral Research Informed Consent**

Title of Study: *The Lived Experience of Hope at End of Life among U.S. Military Veterans*

Principal Investigator (PI): Jaime Huffman

Nursing

**Purpose**

You are being asked to be in a research study examining hope at the end of life among U.S. military Veterans because you are a U.S. military Veteran who has been diagnosed as having a life limiting illness. This study is being conducted at Hospice of Michigan. The estimated number of study participants to be enrolled at Hospice of Michigan is about 6 throughout Eastern Michigan. **Please read this form and ask any questions you may have before agreeing to be in the study.**

In this research study, U.S. military Veterans are being asked to share their experiences of hope. Hope has been shown to be a very important factor to promoting quality of life in terminally ill patients. However studies about hope among U.S. military Veterans have yet to be conducted. This research would afford you the opportunity to give voice to your beliefs about hope and potentially help promote quality of life in your fellow Veterans.

**Study Procedures**

If you agree to take part in this research study, you will be asked to complete a 3 minute assessment of your abilities of recall. Information about your service as a Veteran, such as branch, rank and years of service will be collected. The researcher will also ask you to describe what hope means to you and how it impacts your life.

**1.** You will first fill out a survey which assesses recall abilities. This survey will take approximately 3 minutes.

2. Next you will be asked to provide the researcher with information about your service as a Veteran. The researcher will ask you what your highest rank in the military was, how many years you served, which conflict you served in, if you were a combat Veteran and how you perceived your service. This should take 5 minutes.

3. You will be asked to describe what the word hope means to you and how hope impacts your life. The allotted time for this conversation will be 60-90 minutes.

4. *You have the right to refuse any questions you do not wish to answer and may stop the research interview at any time.*

5. *Once we have finished our research interview the researcher will not contact you again.*

6. Your name and identifying information will only appear on the consent form. You will be given an alias in the study and only the researcher will know your identify. This information will not be shared with anyone.

### **Benefits**

As a participant in this research study, there may be no direct benefit for you; however, information from this study may benefit other people now or in the future.

The possible benefits to you for taking part in this research study are to share your experience as a Veteran which will be shared with others. Your insights may help health care professionals who care for Veterans at the end of life.

### **Risks**

By taking part in this study, you may experience the following risks:

- *Emotional risks (e.g., feelings of sadness or anxiety)*

The following information must be released/reported to the appropriate authorities if at any time during the study there is concern that: include applicable bullet(s)

- child abuse or elder abuse has possibly occurred,

- you have a reportable communicable disease (i.e., certain sexually transmitted diseases or HIV)
- you disclose illegal criminal activities, illegal substance abuse or violence

There may also be risks involved from taking part in this study that are not known to researchers at this time.

### **Study Costs**

- Participation in this study will be of no cost to you.

### **Compensation**

You will not be paid for taking part in this study.

### **Confidentiality**

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. You will be identified in the research records by a code name or number. Information that identifies you personally will not be released without your written permission. However, the study sponsor, the Institutional Review Board (IRB) at Wayne State University, or federal agencies with appropriate regulatory oversight [e.g., Food and Drug Administration (FDA), Office for Human Research Protections (OHRP), Office of Civil Rights (OCR), etc.] may review your records.

When the results of this research are published or discussed in conferences, no information will be included that would reveal your identity.

If photographs, videos, or audiotape recordings of you will be used for research or educational purposes, your identity will be protected or disguised. During the course of the study and for one year following the research tapes will be kept in a locked file cabinet separate from your signed consent form. After that time all files will be destroyed.



### **Voluntary Participation/Withdrawal**

Taking part in this study is voluntary. You have the right to choose not to take part in this study. You are free to only answer questions that you want to answer. You are free to withdraw from participation in this study at any time. Your decisions will not change any present or future relationship with Wayne State University or its affiliates, or other services you are entitled to receive.

The PI may stop your participation in this study without your consent. The PI will make the decision and let you know if it is not possible for you to continue. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study

### **Questions**

If you have any questions about this study now or in the future, you may contact Jaime Huffman or one of her research team members at the following phone number. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

### **Consent to Participate in a Research Study**

To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

\_\_\_\_\_  
Signature of participant / Legally authorized representative \*

\_\_\_\_\_  
Date

_____		_____
Printed name of participant / Legally authorized representative	*	Time
_____		_____
Signature of witness**		Date
_____		_____
Printed of witness**		Time
_____		_____
Signature of person obtaining consent		Date
_____		_____
Printed name of person obtaining consent		Time
_____		_____
Signature of translator		Date
_____		_____
Printed name of translator		Time

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**ABSTRACT****HOPE AT THE END OF LIFE AMONG U.S. MILITARY VETERANS**

by

**JAIME L. HUFFMAN****December 2013****Advisor:** Dr. Stephanie Myer Schim**Major:** Nursing**Degree:** Doctor of Philosophy

The purpose of this research study was to examine the meaning of hope at the end of life among Veterans. As people enter the terminal phase of life hope becomes especially important. Recent research has been conducted examining hope among various cultural groups and their experiences of the phenomenon. These studies showed that although hope is a universal phenomenon, different cultural groups ascribe different meanings to it. These cultural variations are important for nurses to consider when caring for patients.

Research conducted among Veterans has shown that as a cultural group, Veterans have different experiences and needs throughout their lives than do their non-veteran peers. Yet little is known about their lived experiences at the end of life. While a small amount of research has been conducted with this cultural group at the end of life, no studies could be found in which Veterans were able to express perceptions of hope at the final stage of life.

This study used a phenomenological research design to examine hope at the end of life among Veterans. The researcher interviewed 7 Veterans receiving hospice care through a home health hospice agency. The researcher used Giorgi's procedural modification for descriptive phenomenology to analyze the data.

The findings from this study showed three major themes. They were the 1) Nature of Veterans'

Hopes, 2) Targets of Veterans' Hopes and 3) Shared Values of the Veterans. All of these findings suggest that while many of the ways Veterans experience hope at the end of life is typical of persons with terminal illness, there are some themes unique to this cultural group. The findings from these studies could be helpful to nurses caring for Veterans at the end of life.

### **AUTOBIOGRAPHICAL STATEMENT**

I received a bachelor's degree from Western Michigan University in 2001. Shortly after passing the NCLEX I began working on a medical ICU floor at a large urban hospital. There I cared for many patients who were terminally ill and was privileged to share in their end-of-life experiences. These first hand encounters with the differences of care preferences among terminally ill patients peaked my interest in individual end-of life experiences.

After working full-time as a RN for a year and a half I entered the master's program at Saginaw Valley State University. There I discovered my love of teaching and began working as a clinical instructor with the fundamental students in long term care facilities. I was also working part-time as a RN in a local medical ICU. Once again, I shared in the individual end-of-life experiences of multiple patients. During these care encounters I noticed the hopes that patients and their families expressed in the last few days of the patients' lives. For my master's thesis I used a qualitative methodology to investigate the lived experience of hope among chronically ill individuals.

The fulfillment I found in teaching baccalaureate nursing students took me away from bedside nursing when I accepted a full-time faculty position at Saginaw Valley State University. I loved my teaching position, but was still intrigued by the end-of-life experiences I had witnessed as a RN over the past five years of direct patient care. I entered the doctoral program at Wayne State University to investigate individual lived experiences at the end of life.

During my doctoral studies I was hired as part-time faculty on a national grant. The grant was a partnership of our university with a local VA hospital. My interest in the cultural differences of Veterans was peaked and I soon began writing my assigned class papers around this population. In 2007 I became ELNEC-trainer certified and in 2010 I earned ELNEC-Veterans certification.