Published in final edited form as:

J Hosp Palliat Nurs. 2016 June ; 18(3): 219–226. doi:10.1097/NJH.0000000000000250.

Confronting Mortality: Narratives of Military Veterans Enrolled in Home Hospice Care

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INTRODUCTION

Nearly 642,000 US military veterans die each year, accounting for one in four deaths in the US.¹ However, the great majority (85%) of veterans do not receive health services through the Veteran's Administration (VA),¹ and only 4% of veteran deaths actually occur within VA facilities. Of the 15% of former military who do access the VA system for some care, many continue to utilize non-governmental facilities for selected services, such as hospice. Approximately 1.54 million people used hospice services in 2013 (41.9% of all deaths).² Yet, most of what we know about end of life needs and preferences of veterans has come from VA data and therefore reflects only a small proportion of veterans who use the VA for end-of-life care.

Hospice provides a vital care delivery system to understand veterans at the end of life and to determine whether their needs are different as compared to those who have not served in the military. Some studies and case reports suggest that veterans may face unique challenges as they cope with the end of their lives and may be further impacted if there was combat exposure.³⁻⁶ Spiro et. al⁶ speculated in seminal aging research that military service is a “hidden” variable and may have long-term effects in increasing the risk for PTSD and its accompanying psychological sequela over the course of the life span. Other studies have reported that veterans may confront unresolved guilt or shame related to wartime experiences as they near the end of their lives.⁴ However, most of these studies have been conducted with veterans who are enrolled in and receiving care from VA medical centers and affiliated institutions. To our knowledge, no study has specifically investigated the lived experience of being a veteran enrolled in home hospice care. The overall purpose of this study is to advance the understanding and meaning of the experience of the veteran who is enrolled in home hospice care within the context of a terminal illness.

METHOD

Study Design

A phenomenological, hermeneutic, qualitative study was planned to advance the understanding and meaning of being a veteran enrolled in home hospice care. Lindseth & Norberg⁷ describe this methodological approach as focusing on the essence and the underlying meaning in different phenomena of lived experiences. Phenomenology seeks knowledge on the basis of the genuine, human experience and relies on narratives that aim to understand the lived experience of human beings. Hermeneutics suggest that experiences are essentially structured through interpretations of the world and the meaning that is ascribed to those experiences. This interpretative process of meaning-making is based on non cognitive as well as cognitive understandings and through this interpretation, an understanding is shared. Phenomenology attempts to elucidate the hidden meaning of life experiences, while hermeneutics tries to find meaning through interpretation of the expressions of life. Three general, overarching foci were utilized: 1). to discover the meaning of important life events and life review within the context of being a veteran; 2). to discover if and how emotions may be associated with these memories; and 3). to understand if the military experience shaped or influenced these memories.

Participants and Setting

Fifteen adult terminally ill veterans who resided in their private homes in a community setting were purposively selected from a large, nonprofit hospice program in the Midwestern United States. Purposive selection included those veterans who served in different military branches, including combat and non-combat service, and age. Participants needed to demonstrate satisfactory cognitive status on the Short Portable Mental Status Questionnaire⁸ (eg. fewer than two errors), be able to state their physical pain rating was at an “acceptable” level, and voluntarily agree to be voice recorded. Ethical approval was obtained from the institutional review board of University Hospitals Case Medical Center of Cleveland, Ohio and informed, written consent was obtained at the time of the interview.

Procedure

The PI of this study introduced and described the overall purpose of this study to members of the interdisciplinary teams affiliated with a large not-for-profit hospice provider. This hospice provider endorsed the use of the Military History Checklist, proposed by the *We Honor Veterans Program*, part of the Department of Veteran's Affairs and endorsed by the National Hospice and Palliative Care Organization (NHPCO).⁹ This short form identified veteran status (y/n), branch and time of service, combat, and possibility of VA benefits. Hospice nurses and social workers initially introduced the overall purpose of the study to veteran participants who met the eligibility criteria. Once the hospice team member ascertained participant interest, the PI obtained eligible participant demographic information and within 24 hours, the participant and PI established a mutually acceptable time to meet. All participants received an explanation of the study and informed consent was obtained to conduct the interviews.

Interview Process

Because an understanding of the phenomenon or experience was sought, in-depth voice recorded semi-structured interviews were conducted. An interview guide, developed by the PI, was used to aid in the facilitation of the interview. The guide was not used to limit the content of the interview but ensured that important questions were asked. At completion of the interview, participants were asked whether they would be willing to be interviewed again within a week. The purpose of an additional interview, also known as member checking, was twofold: it allowed for the opportunity to clarify and validate the previous conversation and to establish the viability of the interpretation of the participant's narrative. Although this second interview was neither required or feasible (due in part to participants' declining cognitive status), the PI conducted second interviews with three participants.

Data collection and analysis

Data collection and analysis were conducted simultaneously to ensure that findings from initial interviews were followed and explored in greater depth in later interviews. All interviews were conducted in the participant's private home residence and the average length of time of the interview was 75 minutes. New participants continued to be recruited during the interview process until no further themes emerged and theoretical saturation was achieved. Field notes were recorded by the PI prior to and following the interview. To ensure confidentiality, no names were included in the transcripts.

As a precaution for potential distress, based on the sensitive nature of the open ended interview guide and the chance to raise painful topics, including war memories, past hurts, and perhaps relational conflict,¹⁰ the Primary Care Post Traumatic Screen (PC-PTSD)¹¹ was used to determine if PTSD symptoms were present before interviewing subjects. Current research suggests that the results of the PC-PTSD should be considered "positive" if a patient answers "yes" to any three items. If one or more of the questions was answered "yes", the National Institute of Mental Health handout on PTSD¹² was given to the participant and he/she was asked whether or not he/she would prefer to continue with the interview process, and not participate, or reschedule for a later time. While our analysis did not focus on comparisons between combat and noncombat experiences and the potential psychosocial related effects, it was prudent to screen for PTSD symptoms in all participants. Only one participant screened positive for PTSD, according to the PC-PTSD instrument; this individual decided to continue with the full interview.

All interviews were transcribed verbatim and analysis was guided by the Giorgi¹³ method as outlined by Omery¹⁴. The Giorgi method of analysis consisted of five steps: each transcript was read to get a sense of the whole; individual constituents of the experience were identified; coding was based on emerged categories and identification of essential meanings; and new data were compared and contrasted until themes emerged. The final step of the analysis involved the synthesis and integration of the various themes into a description of the phenomenon that was enriched with illuminating parts of the text. The PI and another investigator of this study individually read and coded the first three transcripts. Interview questions were modified based on the codings. The research team then met again after the eighth interview, compared coding, resolved discrepancies, and added new codes as needed.

Subsequent transcripts were individually coded by the two investigators, who met regularly to discuss the analyses, clarify their inductive thinking, debate differences in interpretation and meaning, and reach consensus regarding the interpretations. Preliminary analysis involved open coding, or the assignment of labels to words or phrases representing key categories. Analysis within and across the interviews resulted in identification of recurring themes.

Criteria for trustworthiness developed by Lincoln & Guba¹⁵ guided verification that the qualitative analysis represented the data. Credibility was achieved by several means, including coding that was performed jointly by the principal investigator and the research team. Formal member checking was carried out with the first and eighth participant through an additional interview to ensure that the analysis of the initial transcript was valid. A reflective journal with records of logistics and methodological notes, including memos written during the course of the study, served as the criterion to establish confirmability.

FINDINGS

Fifteen US military veterans representing three military branches of four war periods agreed to participate in this study. Demographic data are presented in Table 1. The mean age was 76.9 (range= 56-95). Participants' performance status was determined by the Palliative Performance Scale (PPS)¹⁶. Scores can range from 10 (bedbound) to 100 (full ambulation). The mean PPS score of this sample was 40 which indicated lower levels of physical functioning and presence of extensive disease. Five themes emerged that described the meaning of being a veteran enrolled in home hospice care: limited opportunities, broken relationships, obligation, military service as a life influence - not definition, and lack of fear/acceptance of death.

Limited opportunities

Most veterans described their experience and time in the service as not so different from life before entering the military. Many discussed how their lack of choices regarding life opportunities were largely related to socioeconomic and education disadvantage. Several participants mentioned how aberrant behaviors, including alcohol and drug abuse, as well as being raised in environments where these behaviors existed, exerted a profound effect on the choices they made in life. Subsequent to this, conflict with authority figures, including police and school officials, and related consequences, further fueled their desire to escape from their reality. Almost all of the participants referenced a desire to leave their pre-military living environment as an opportunity for a different life.

“...you either sign up or you go to the detention home...I went [in the service] to get away from life here”

“In 1979, after the whole war deal, I had to go to the penitentiary, and that's not a pleasant thing. In fact, that's uglier than Vietnam was”

“I joined the [branch], and I really didn't want to go, but I was kinda bad in school. I was kinda raised in foster homes and everything in orphanages and stuff, so I

didn't really have anybody to discipline me and so they says you know you need to join the Service”

“I had to get the hell out of town...which is the reason why an awful lot of guys got into the service...it's a chance for a different life, which is what I got...up through 18 years I was a bag of shit in town, useless person...I had to go to find a new way of life.”

Broken relationships

The theme broken relationships conveyed veterans’ experiences of fractured relationships with at least one if not both parents, being witness to divorced parents (before war) or having experienced divorce (post service time), actively engaging in family conflict after return from service, or feeling abandoned and disengaged by the VA. Most participants discussed the feelings of watching and hearing violent conversations among their family members as a young child and through their young adult lives. Some of the participants were sons of military fathers and were deeply committed to making them proud, although there was an existing fracture in their relationships. Others spoke about how transgressions in their personal and social relationships seemed to propel them toward a desire to want a camaraderie-type relationship – one that is often found and coveted in the military experience. For most of the participants, reuniting with family or creating new relationships after wartime was often met with challenge but at the time of their interviews, all had found a sense of repair or healing of the brokenness.

Several participants highlighted a sense of mistrust and lack of fulfillment of promises, critical transgressions of relationships, of the VA health system. Of the total sample, 67% (n=10) were enrolled in the VA (registered in the health system). Of those who were enrolled, only six veterans (40% of total sample) received benefits from the VA (actually received some health care service from the VA). (See Table I).

“My childhood and relationships with my mom and dad were terrible...cause her and I didn't get along...that affected me more than my entire war time...I joined the [branch]...I went to kiss my mother and hug her about 5 in the evening before I left... ‘go to hell’ ...she said in Slovak. I'll never forget that”

“My dad was a big alcoholic and he didn't support us or nothing, you know. When I got back from Vietnam, I got married and obviously that didn't turn out so good either”

“The VA never informed us of anything, so I got mad and says if this is how the government works, I don't want no part of it. So I quit getting it”

“I have seen them [VA] one time, but they're not very helpful...I don't think I could rely on them... and then it takes so long to wait to be there anyways...”

Obligation

Every veteran expressed that serving in the military, either drafted or enlisted, was not a choice; in fact, it was simply what one did. This sense of obligation was either born out of necessity to escape the realities of life as it was before the military or to follow the tradition

of military service of family members (specifically, grandfathers, fathers, and brothers of participants). Most participants spoke about this obligation as a duty of service and did not speak of a desire to be honored or acknowledged. Participants openly shared how people, including family, friends, and health care providers, were often quick to offer gratitude for their service through words or gestures such as ‘pinning ceremonies’. See Table I for frequencies of pinning ceremonies among participants. Most did not desire “being honored” or being identified as “heroes” although ten out of fifteen participants had been formally pinned by the hospice teams. Their narrative described a sense of social force that others felt incumbent to act stemming from societal norms rather than individual experience and the importance or lack of that experience.

“It was just everyone did it...my brother did it...he was there because he had to be there...he had no choice...he wasn't a hero...he served because he had to be there...that's the reason we were there...that's the reason I was there...I am a regular guy...”

“Service is just part of your life...it's your duty. I think it's everybody's duty to join up and serve their country...I did nothing out of the ordinary...I just did my job.”

“Heroes are the ones who didn't make it... the ones that ain't coming home...I'll give you the praise and honor you should have, but you're not my hero or anybody's hero...so the guys that can't speak for themselves...who went there because it was their duty...they're the heroes that aren't going to be able to come back and enjoy life no more”

Life influence not definition

Most participants who were in active combat and some who identified as serving in a noncombat role shared deep feelings of guilt for having survived catastrophic events when others were not spared. This “survivor guilt” was often described as not having done enough to save a comrade. Positive and negative reflections about these emotions were polarized with an extreme sense of gratitude, both for having survived and returning to their country and having had the experience to give organization and order to their lives. This gratitude for ‘gaining order’ was not related to their narrative to previous comments about a chaotic life pre-military. All participants were able to keenly recount their war experiences, yet most of them did not connect their time in service as a core identity of who they are now. Many of the veterans described how being in the military was formidable or ‘shaping’, but most began to take an inventory of their life and relationships when they became aware of their terminal diagnosis. Most of the participants looked “death in the face” during their service experience; however, their narratives illustrated how the natural death process they were currently living focused on their whole person and their life course, not simply the life connected to their service time.

“I feel guilty because I came back...you know you always ask, ‘why me?’ ...but I guess there is a reason...it's been more good than bad...I wasn't the best father, but now I have a relationship with my kids.”

“I was a fighter pilot in WW2...got my commission and wings in the [branch]...but that didn't formulate my life...my wife and marriage did...my son and daughter-in-law did...”

“The happiest day of my life was when I got outa Vietnam...I was an alcoholic though...I think it would of been worse though without the military...it makes you shape yourself up a little....the whole time I was influenced by it....I'd probably still be living with my mother without it...but here I am now...in my own house... even though I am dying I have this wonderful spouse, I can take care of my car, and I have my family...”

Lack of fear/acceptance of death

All veterans in this study were pragmatic and open about their impending death and awareness of limited time. While most of the veterans shared detailed stories about how they wished things could have turned out better, these ‘regrets’ were reconciled and accepted; all of them stated that if they died [today], they were prepared, not angry, or fearful. Some had attempted to mend past transgressions with the help of the Twelve Steps of Alcoholics Anonymous; others had healed intrapersonal hurts through generativity acts such as sharing wisdom through lessons learned. Overall, there was an intense lack of resistance against death.

“I've covered the bases...I know I'm dying...I tell people I'm not afraid of being dead...everyone does that”

“I want to get out of here...I want to go...I have no regrets...I don't need anything...I am just a regular guy who is ready to die”

“If you get the impression that I am totally at peace, I am...enjoy life as you get it. When you got it, enjoy life cause it's really ...it's really too short. That's been said a million times, it's too short, and there's really nothing to worry about.”

“I've made my mark. I've made my mark through these three kids and my grandchildren”

DISCUSSION

This study has unearthed some key findings about the meaning of the lived experience of being a veteran at the end of life who is enrolled in home hospice care. Most informative to the care of veterans receiving home hospice care, as it relates to narratives of participants in this study, was that being a veteran was not their core identity at the end of their lives. This finding is consistent with the general end-of-life population and described by Cassell's theory of personhood¹⁷. Each person is a holistic being with dynamic, interrelated dimensions that are affected by lived experiences and the changes and adaptations that are experienced in the face of a life-limiting illness. Life perspective, goals, and needs change as more reflection allows for a broader sense of meaning, purpose, and relationship, based on each individuals' values. In many ways, veterans face the end of life in a similar way as civilians. According to Grassman,¹⁸ not all patients will maintain their identity as a veteran; however, if they do, the context of the relationship will be shaped by the military culture.

Most studies about veteran hospice use and care of veterans at the end of life have been generated from VA data sources and results are often applied to all veterans who are at life's end. Certainly there is overwhelming evidence that traumatic events can produce many negative psychological consequences.¹⁹ However there also is significant research suggesting that people, including veterans, exposed to even the most traumatic events may perceive at least some good emerging from their struggle with tragedies.²⁰

At least three broad subcategories were identified within these narratives including changes in self-perception, changes in interpersonal relationships, and a changed philosophy of life. Similar to findings about post-traumatic growth,²¹ this study's results illustrated that most participants' post war reflections offered them the ability to recognize the importance of the experience in a positive light. These findings are also consistent with specific developmental tasks proposed by Steinhäuser et al²² that outlined specific developmental tasks: sense of completion in relationships, exploring issues of regret and forgiveness, sense of gratitude and appreciation, life review and transmission of knowledge and wisdom. These tasks have been identified as components of domains of end-of life preparation and completion and can be applied to all people at the end of life, including veterans. This study's findings suggest that although limited opportunities existed in life, at the end of their lives, most veterans in this study found meaning and purpose.

Although trauma exposure is ubiquitous among almost all veterans, regardless of branch or war period, the prevalence of diagnosed PTSD is relatively low,²³ despite the fact that veterans also experience higher rates of pre-military trauma than the non-veteran population.²⁴ In fact, the previous data about the prevalence of pre-military stresses, personal crises, and traumatic experiences may explain why families of veterans have reported greater needs for emotional support than families of non-veterans. Using data from the Family Evaluation of Hospice Care survey (FEHC) of 560 hospice veteran caregivers who had received care from an urban hospice in the US, Holland and colleagues²⁵ reported that caregivers of veterans in hospice care were more likely to report that the veterans experienced increased anxiety and sadness as compared to those who cared for nonveterans. Furthermore, veteran caregivers were more likely to report a greater need for bereavement services as compared to nonveteran caregivers. As one participant so eloquently stated:

"I think the closer you are to the [war], the more importance you place on it. The farther away we come from that, the less important it is because it's just like a season of life... I know that when my dad died (who was also a veteran), we had military honors at the gravesite...that was just for us...we were so thrilled to see that for our dad, even though he could have cared less (you know, he's dead). But, for us, it was an important thing, and to this day I couldn't tell you the reason why".

There are veterans for whom honoring and acknowledging service is appropriate. However, it should not be customary that honoring is a fundamental gesture at the end of life, specifically for the veteran him/herself.²⁶ Although this gesture is intended to be one of respect, it might be viewed as disrespectful, especially if not wanted or desired. One participant shared:

“Why should there be any importance attached to something you should do, without necessarily being asked? Just do it. It was my duty and don't honor me for it. I did my job.”

Finally, narratives describing the mistrust and broken relationships with VA health system might be associated with lack of knowledge about how services are rendered, the fragmented coordination of care, convenience related to distance of nearest VA facility, wait time, and most importantly, the lack of clear communication between and among providers.

Similar to Wachterman et al²⁷ findings, most of the participant's conversations about receiving hospice benefits were initiated by primary care physicians or oncologists outside the VA health system. The need for education about services and reimbursement structures extends beyond the community hospice and VA providers to the more general public. The Hospice-Veteran Partnership Toolkit,²⁸ jointly sponsored by the VA and NHPCO, may eliminate some of these barriers and provide structure to the coordination of care for veterans at the end of life.

LIMITATIONS

This study was conducted with veterans who were primarily Caucasian and male and who were enrolled in one, large community-based hospice program. Although the demographic characteristics of gender and ethnicity are consistent with most veterans who served in the WW2-Vietnam time period, they are not representative of all veterans. In particular, the fact that these participants were not actively receiving their hospice care from the VA is likely to be related to dissatisfaction of the participants with VA services and thus not representative of all veterans. The sample size does not allow for generalizability; however, this is not the goal of phenomenological inquiry. Rather, it is to elucidate the presence of multiple realities and describe their meanings.

IMPLICATIONS FOR NURSING

The most important insights from this study are in clarifying and raising questions about what have been previous assumptions about veterans at the end of life. As noted in the introduction section, there is a risk that all veterans are presumed to have PTSD or have the propensity to display characteristics based on their wartime experience. Although the prevalence of PTSD symptoms was almost nonexistent in this sample, this emphasizes that thorough PTSD screening should be performed once a hospice provider/veteran relationship is established rather than relying on assumptions about this population. The use of the PC-PTSD screen has been endorsed by the National Institute of Mental Health (NIMH) and the US Department of Veterans Affairs and should be integrated into the care of the veteran at end of life. There is much within existing veteran resources that aims to assist with end-of-life care. Specifically, *We Honor Veterans*²⁹, a program of the National Hospice and Palliative Care Organization (NHPCO) in collaboration with the Department of Veterans Affairs (VA) invites hospices, state hospice organizations, and VA facilities to join resources and educational tools to increase access, integrate best practices, and improve care deliver to veterans at the end of life. Moreover, it is vital that communication efforts, between VA health care teams who are engaged in end-of-life care for veterans and their families, and

community based hospice programs, remain at the forefront of coordinated care for veterans. Place of care for veterans at the end of life should be determined commensurate with individual goals of care and how those will be achieved through the plan of care and the interdisciplinary team.

Finally, what may be the gap in the understanding of how wartime shapes the end of life experience may rest in the family members' or caregivers' perception. Consistent with the hospice philosophy where care is intended to be provided to the patient and family unit, caregiver expectations and perceptions are important elements of emotional support and satisfaction of care.²⁵ The meaning of being honored and subsequent acknowledgement may be more important and relevant to those who care for veteran (eg. family caregivers) than the veteran him/herself. Therefore, prior to any formal veteran pinning ceremony, hospice care providers should assess the veteran and his/her family about the meaning of the ceremony, its importance, and seek verbal consent. Again, it should not be presumed that being a veteran connotes the desire to be honored for having served in the military. In collaboration with the VA, NHPCO has developed Veteran-Specific Questions (formerly known as Family Evaluation of Hospice Care-Veterans - or FEHC-V) to help hospices evaluate the care they have delivered to their Veterans patients. Veteran Specific Questions (VSQ) is a post-death survey designed to yield actionable information that reflects the quality of hospice care delivery from the perspective of family caregivers. In addition, the Military History can be used to identify veteran status, to evaluate the impact of war experience, and to determine if there are benefits to which the veteran and surviving dependents may be entitled. Just as health care and hospice providers should not use a "one size fits all approach" to deliver quality end-of-life care, veterans' individualized plans of care should be developed based on validated screening and assessment tools that include both military and non-military questions.

CONCLUSION

The face of America is aging. Half of the men who die every day in the United States are veterans. Millions of Americans who served in World War II and in Korea are now 80-90 years old; Vietnam veterans are reaching the age of 70. As part of health care providers' obligations to this aging population, end-of-life care should be evidence-based and tailored to meet specific needs of each veteran and his or her family. Most importantly, hospice clinicians should first address and assess the terminally ill veteran as a person who has had a lived experience of being in the military with various meanings of the experience and the importance or lack of importance he or she attaches to it. These narratives suggest that hospice providers, whether affiliated with the VA or community based programs, should not assume that being a veteran and having that status automatically warrants differential treatment. Generalizing conclusions from veteran studies should be used with caution as these narratives suggest that veterans enrolled in home hospice care need to be acknowledged as whole persons in the spectrum of adult development. With this perspective, their military experience may be influential and unique, but not life-defining.

Acknowledgments

Funded by: NIH/NINR 1P30NR011907-01

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TABLE 1

Subject	Age	Sex	Ethnicity	Dx	PPS*	Military Branch	War Period	Active Combat	PTSD	Pinned	Enrolled in VA/Receiving Benefits
1	81	M	Black	Prostate CA	40	Army	Korean	Y	NO	YES	YES/YES
2	70	M	Caucasian	Lung CA	40	Army	Vietnam	N	NO	YES	YES/YES
3	78	M	Caucasian	Parkinsons	40	Army	Korean	N	NO	YES	NO/NO
4	87	M	Caucasian	COPD	35	Army	WW II	Y	NO	YES	NO/NO
5	64	M	Caucasian	Pancreatic CA	50	Marines	Vietnam	Y	NO	YES	YES/NO
6	69	M	Caucasian	Renal CA	40	Navy	Cold War	N	NO	NO	YES/YES
7	86	M	Caucasian	Heart Failure	30	Navy	WW II	N	NO	YES	NO/NO
8	65	M	Caucasian	Lung CA	45	Army	Vietnam	Y	YES	YES	YES/YES
9	84	M	Caucasian	Prostate CA	50	Army	Cold War	N	NO	NO	YES/NO
10	82	M	Caucasian	Heart Failure	40	Army	Korean	Y	NO	NO	YES/NO
11	88	F	Caucasian	Pulmonary HTN	30	Navy	WW II	N	NO	YES	NO/NO
12	95	M	Caucasian	HF	30	Army	WW II	Y	NO	NO	YES/YES
13	69	M	Caucasian	Prostate CA	50	Army	Korean	N	NO	NO	YES/YES
14	80	M	Caucasian	Lymphoma	50	Army	Korean	Y	NO	YES	NO/NO
15	56	M	Caucasian	Liver CA	50	Marines	Vietnam	N	NO	YES	YES/NO

* Palliative Performance Scale