

PERSONAL NARRATIVE

Specialized Palliative and Hospice Care and the Importance of Mourning Our Nation's Veterans

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Abstract

One aspect of palliative medicine that has been underexplored is the perspective of veterans either facing critical life-limiting illness or at the end of life. The needs of veterans differ not only because military culture affects how veterans cope with their illness but also because exposure-related factors (combat and environmental) differ between military branches. In this paper, we describe two cases involving end-of-life care for veterans with combat trauma and describe individualized approaches to their care.

End-of-Life Care for Veterans with Histories of Combat Trauma

Palliative and hospice care in any setting pose opportunities for tailoring care to unique patient populations. In Veterans Affairs health care facilities, the influence of military culture is felt throughout the delivery of care. One particularly striking challenge is caring for veterans who have a history of combat trauma. This challenge is especially poignant as these same veterans might be facing an illness that is likely to shorten their lifespan. Therefore, it is of paramount importance to assess for traumatic memories associated with the time spent in the service and adapt plans of care appropriately. In the cases below, we elucidate these challenges in the hopes of increasing awareness and understanding of this patient population.

Case 1

W.D. was in his 60s when he was admitted to our hospice unit with end-stage liver disease due to alcohol intake. He was a Vietnam veteran who had served 6 consecutive, 1-year active combat deployments. Following his military service, he became a member of the Ku Klux Klan (KKK) and neo-Nazi organizations. W.D. had acknowledged difficulty reassimilating into civilian life, and it is possible that he joined these organizations to experience a sense of belonging and validation after the war-related atrocities he had committed. When he arrived, it was clear that he was angry, was minimally interactive with all staff, and had great difficulty allowing any physical care by a person of color. On a nearly daily basis over the first weeks of his admission, he described in graphic detail his combat experiences, telling staff regularly that because of his life choices he was evil. He

made these revelations not only to horrify staff members but also to push them away and avoid developing a more meaningful response to the care team.

Following these exchanges, boundaries were set for acceptable behavior, the violation of which entailed immediate disengagement and cessation of the visit. Simultaneously, W.D. was consistently reminded that he would continue to be cared for and would not be abandoned. His resistance to trusting the clinicians around him stemmed largely from combat trauma over his 6 years of active duty. He vacillated between begging for symptom management and refusing to take medications. The rationale for this refusal originated from his belief that, as a soldier, showing pain equated with weakness. Furthermore, he felt his symptoms were retribution and necessary suffering for the atrocities he had committed during and after his military service. He experienced great existential distress, as he could not reconcile the love he felt from the people around him with his previously held prejudiced ideas and thoughts, which he clung to because they had formed the basis of his identity. Over the months that he was cared for on our hospice unit, his attitude towards the staff changed from one of contempt to one of care and acceptance. As staff members showed him respect, demonstrated compassion despite his hostility, and displayed consistency in their approach to care, his behavioral outbursts lessened in frequency and intensity and eventually disappeared altogether. Over time, he was able to recognize his own capacity for love and to be loved by others, including the people he was initially prejudiced against. When he was nearing the end of life, he expressed to the [chaplain](#) that while he was grateful to the staff, he felt deep regret that his life had no value and felt that no one would remember him after his death. Our chaplain eloquently responded, "We will mourn you." This simple sentiment—and all the care he had received beforehand—allowed a peaceful death for this tortured soul.

Case 2

G.A., an Operation Iraqi Freedom veteran, was only 50 years old when he was diagnosed with stage IV adenocarcinoma. At initial diagnosis, he received a colonic stent for obstruction and multiple rounds of chemotherapy. Our team met him for an initial palliative care consultation approximately 5 months after his diagnosis. Unfortunately, by this time his cancer had already metastasized to his liver despite aggressive treatment regimens. Much of our initial visit did not focus on G.A.'s terminal cancer diagnosis but rather on his military experience, as it was clear that G.A. was struggling with another major health problem that had never fully been addressed. G.A. was a commander in the Army and was deployed to Iraq from 2004 to 2005. Like many veterans with combat exposure, G.A. suffered from severe [posttraumatic stress disorder](#) (PTSD) that had been ongoing since he returned from his deployment. He was very candid with us in sharing his experiences and quickly became tearful during our interaction in his hospital room. He disclosed that because his PTSD made him claustrophobic and unable to cope with reality, he often could not reside in his own home with his wife and son but rather lived in a tent in the backyard. G.A. prided himself on his

strength in battle and life, but it was clear that he never fully reassimilated into civilian life. He also described himself as “thick headed,” with a high tolerance for pain. Our team knew that as this particular veteran progressed in his illness, both PTSD and potential underreporting of symptoms were likely to become obstacles in his care.

G.A. was again hospitalized for an obstructed colon and stent replacement. During this admission, he became delirious, believing that medical staff members were holding him in the hospital against his will. Because of the severity of his agitation, he required physical and pharmacological restraints to ensure his safety and that of the staff around him. Afterwards, he poignantly described this experience as being like “an animal in a cage ... with no escape.” Eventually, G.A. stabilized and was discharged home to his wife and teenage son, but he soon developed refractory ascites and required paracentesis repeatedly. G.A. was never forthcoming in sharing his symptoms and required much prompting and encouragement from our team and the home care nurses to disclose his symptoms. It was a continuous balancing act to respect G.A.’s need for independence in his care, allowing him the space he needed to process and cope with his illness, and to feel that we were still adequately managing distressing symptoms. Because of the severity of G.A.’s symptom burden, he eventually required admission on our inpatient hospice unit. But because this veteran had been able to work with our team in the outpatient setting, by the time he came to the unit he was accepting that he was nearing the end of life and allowed all aspects of care provision in the inpatient setting.

Palliative Care for Veterans with Combat Trauma

As civilians working at a Veterans Affairs hospital, we needed time to acclimate to the military culture; adjusting to the language (“tour” vs “shift,” “leave time” vs “vacation”) seemed the most challenging initially. However, it became quickly apparent that our care of veterans was affected by much more striking features than language, and these features changed our approach to care. Developing an understanding of the nuances of the different military branches and of how veteran characteristics vary from one war era to the next is paramount to ensuring each veteran receives individualized care. For instance, a veteran with an Army or Marine Corps background has a greater likelihood of having experienced face-to-face ground combat than a Navy or Air Force veteran. Killing one person who is in front of you has a greater psychological impact than dropping a bomb on a faceless population. In the field of palliative care, the emotional response seen in veterans who have just received a life-limiting diagnosis makes formulating an individualized plan of care even more challenging, just as the emotional challenge of taking care of dying persons on a regular basis adds to palliative care practitioners’ burden.

Ascertaining a veteran’s military experience in order to adapt care must be approached sensitively yet directly, with awareness of nuances. One particular ethical challenge is helping the family to understand how military experience might impact the veteran’s

ability to cope with illness. Here we will focus on another ethical challenge: determining how the experience of military service has shaped the individual patient without undermining the veteran's trust in his or her clinicians. In our cases, the impact of PTSD on both W.D. and G.A. overshadowed their medical illnesses. In particular, W.D.'s illness was a result of alcoholism, which developed in response to his traumatic combat experiences. An additional ethical consideration is that the life-limiting illness that occurs might actually have been caused, directly or indirectly, by being in the service. For example, direct causal relationships have been established between illnesses such as lung cancer and Agent Orange exposure in Vietnam and between Gulf War Syndrome and exposure to burning oil pits in the Middle East.^{1,2} Learning that one's illness was caused by military service can lead to a myriad of emotional responses—anger, sadness, regret, or difficulties in processing the diagnosis and its implications. Finally, while the focus of palliation is alleviation of symptoms, veterans' underreporting of their symptoms stems from military culture and emphasis on stoicism or "fighting" through hardship. Conversely, overreporting or exaggeration of symptoms is also seen, which could be related to concern that [pain might be ignored](#), as it might have been upon return from war, especially for Vietnam veterans. Furthermore, comorbid substance use disorders in this population are a common problem often stemming from undiagnosed mental illness or self-treatment for PTSD that can make treatment with opioids or anxiolytics even more complicated.

These factors not only make assessment and intervention particularly complex but also could result in unnecessary emergency department visits or acute hospitalizations. Extensive and broad efforts have been made within the Veterans Health Administration to offer palliative care services. Notably, at VA Connecticut, the focus has been on delivery of palliative care in the outpatient setting to assess for military trauma, build rapport, and provide continuity across all care settings to minimize veteran distress in living with an illness that will be life shortening.

Challenges for Veterans at End of Life

All enrolled veterans with a life-limiting diagnosis who meet qualifications for hospice-level care are eligible for VA hospice benefits regardless of their service connection.³ However, use of these services might not facilitate achieving a "[good death](#)" outside of an inpatient facility. Lack of social support, challenges with substance use disorders, and combat trauma impeding appropriate interventions for distressing symptoms are only some of the limitations. If a veteran lives alone and has no discernable support network, death at home might not be possible. Notably, community hospice agencies might be unable to enroll a dying person in home hospice without 24/7 support at home. Likewise, the staff of a community agency might not have been exposed to military culture or know how military-related training, combat exposures, or past traumatic experiences can impact care. What is seen clinically on a regular basis, although its prevalence is not easily measurable, is PTSD at end of life. Veterans in the final stages of life who have

been affected by PTSD might experience existential distress during the dying process, which poses unique challenges in symptom control. Lack of appropriate assessment early in the course of advanced illness could limit opportunities to assess for military-related trauma and could potentially lead to families being inadequately prepared for the death of a loved one.

Implications of Care for Veterans with Life-Limiting Illness

Of the estimated 20 million veterans in the United States, just under half are currently enrolled in the VA system.⁴ What can be extrapolated from these data is that, while a significant portion of veterans die within the VA health care system, a significant number die in the community where their veteran status might be unknown or the influence of their military experience not fully appreciated. This circumstance limits effective delivery of veteran-specific outpatient palliative services over the course of a life-limiting illness by failing to ensure that caregivers of veterans at the end of life are sensitive to military culture and aware of PTSD and its effects. The most immediate implication of limited veteran-specific outpatient palliative care is the inability of veterans with life-limiting illness to achieve a reasonable quality of life. A more far-reaching implication is the long-term impact on families throughout the course of the disease as well as family distress during the period of active dying, which could cause protracted or complicated grief. Assessing patients at the end of life for military-related factors can greatly improve the care of veterans and members of their support network. Our veterans have taught us, and continue to teach us daily, how to be better practitioners in this field and to provide compassion, care, and comfort to those who have sacrificed so much for us. To W.D., G.A. and all the rest.... We will mourn you.

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