

Coping with Trauma and Posttraumatic Stress Disorder (PTSD) at Life's End: Managing Life Review

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Meet Frank, a military veteran who is at home receiving hospice care. His time left to live is likely days to weeks, and he is now so weak that he spends all of his time in a hospital bed in the living room. He is not just passively lying there; he spends most of his time thinking back over his life. Some of his memories are pleasant, like fun times in his childhood with his friends. Other memories bring pain and regret, like his first marriage that did not go so well. But where do his three years in the Air Force fit into his life story? For some, time spent in the military can be a proud experience, full of memories that have been shared freely for years. For others, it is the hardest period in life to stop thinking about. In Frank's case, it is the hardest period in his life to know where to *begin* thinking.

Assisting veterans who want to engage in *life review*, which means talking about their memories and the meaning they give to the events in their life, is a privilege. Knowing how to support a veteran who is undergoing life review can be uniquely challenging. The purpose of this chapter is to assist the family member, friend, caregiver, or clinician in their life review conversations with veterans who have experienced trauma in military service. To better understand military-related trauma, the first section of this chapter gives an overview of different types of distress, including Posttraumatic Stress Disorder (PTSD). The second section offers guidance on navigating these conversations with veterans who choose to share and reflect on their lives which, for many, will be for the first time.

TRAUMA AND POSTTRAUMATIC STRESS DISORDER (PTSD)

Exposure to trauma and living with the subsequent post-exposure aftermath has likely always been associated with military service, although it has not

always been labeled and defined as it is today. In the American Civil War era, traumatized veterans were said to have “irritable heart.” Many World War I veterans were labeled as having “shell shock.” In World War II, nervous veterans were said to be afflicted with “battle fatigue” or “neurosis.” Since 1980, the psychiatric community has formally recognized these conditions as Posttraumatic Stress Disorder (American Psychiatric Association, 1980). Many veterans have experienced trauma or lived through harrowing conditions but have not had their lives adversely affected. Other trauma survivors have struggled to live a life that is integrated with society at all and may have a formal PTSD diagnosis. There is a third category of veterans who may not have been diagnosed with PTSD, but are still bothered by experiences with trauma or distress. This section of the chapter will review the emotional, spiritual, and psychological damage from different types of trauma: moral distress, spiritual distress, memories of living in a hostile environment, or exposure to violence, in addition to living with a formal diagnosis of PTSD.

Moral distress

The military experience can place soldiers in situations where they must perform or bear witness to behavior that is in conflict with their personal morals. Litz et al. (2009) use this definition for “morally injurious experiences: perpetrating, failing to prevent, bearing witness to, or learning about acts that transgress deeply held moral beliefs and expectations” (p. 700). The memories of these experiences can be uncomfortable to the point of distraction or distress, and they can be the source of regret or despair throughout life. This can be experienced acutely as veterans approaching life’s end reflect on their military experience. Moral distress can be associated with feelings of guilt or shame. There can also be a strong component of fear of judgment by others. As with other forms of trauma, these feelings and fears can block veterans from sharing their stories with others. Some veterans with PTSD will have a strong component of moral distress as a part of their traumatic experience(s), however, many more veterans live with moral distress who do not meet criteria for PTSD.

Case example

Mr. G is a World War II army veteran. He served honorably for three years and was primarily stationed in Europe and North Africa. As he approached the end of his life, Mr. G was an enthusiastic storyteller about his time in military service. However, there was one subject that he said was still bothering him and

keeping him up at night. He believed there was no justification for American involvement in the European war theatre, and therefore he felt that the acts of violence he had to commit there were unjust. "I had no problem with the Germans. I was mad at the Japanese. They were the ones who bombed us. The Germans didn't do anything to us. I couldn't believe I was being sent over to Europe. I enlisted to go fight the Japanese, and I got sent to fight the Germans. I just didn't feel right about that, and I still don't."

Spiritual distress

Similar to moral distress, spiritual distress is living with memories of behavior that are incongruent with one's religious or spiritual beliefs. Feelings of regret, shame, guilt, and fear are also associated with spiritual distress. Some veterans leave military service with spiritual beliefs intact or strengthened, and they may find peace, resolution, and forgiveness through prayer or discussion with a leader in their faith tradition. Others leave military service with much disruption to their spiritual beliefs. They may strongly question the existence of God after witnessing atrocities on Earth and wonder, "Where was God in this? Why wasn't this stopped? I prayed for this to end, but was my prayer not heard?"

When previously held religious beliefs are no longer held or are questioned, it can be difficult for some and impossible for others to find meaning and reconciliation within those same beliefs. However, that does not mean the search for understanding and meaning ends. Fontana and Rosenheck (2004), writing about veterans' spiritual distress and PTSD, state, "...veterans' motivation for continued pursuit of mental health services does not appear to be primarily greater symptom relief or more social contact. Rather...a primary motivation of veterans' continuing pursuit of treatment is their search for a meaning and purpose to their traumatic experiences" (p. 582).

As veterans approach the end of life, the urgency to find meaning can be intensified. Some will be distressed by a fear of judgment by God for behavior committed during military service. Others will question the existence of God completely and will anxiously wonder what the afterlife will be like or doubt that there will be an afterlife at all. Many will not speak about these concerns at all, but may appear aloof, removed, anxious, cranky, or tearful; clinicians need to consider that these veterans may in fact be experiencing spiritual distress.

Case example

Mr. B is a 66-year-old Vietnam veteran who was drafted into service in 1968. He had just begun dating a girl in his town and regularly attended her family's Quaker church. Just as he was beginning to develop his beliefs about pacifism, he was drafted. Members of the church tried to help him receive conscientious objector status, but since he had a short history in the church, it was denied by his local draft board. While in service, Mr. B experienced intense emotional reactions to participating in the killing of enemy soldiers and even, inadvertently, many civilians. Following his time in service, Mr. B married his high school girlfriend and continued a lifetime of involvement in the Quaker church. However, he never felt comfortable discussing the violence he committed or witnessed in Vietnam. As he entered what was his last weeks of life, he felt like he was "bursting" with guilt over taking others' lives and "not trying harder to get discharged or sent somewhere else." He died believing God forgave him, but he never gave indication that he forgave himself.

Trauma from a hostile environment

Prolonged exposure to a hostile environment, even without experiencing or witnessing violence, is in itself a traumatic experience. Fontana and Rosenheck (1999) describe elements of a "malevolent environment" (p. 118) that veterans may have experienced, including horrendous weather, exposure to dangerous insects and animals, insufficient supplies, starvation, and lack of shelter. Living under the threat of violence or learning of the death of a comrade also contributes to a hostile environment. King, King, Gudanowski, and Vreven (1995) state that of all stressors that contribute to PTSD, a "malevolent environment appeared to be the most potent factor for men and women" (p. 192) who served in Vietnam. In the later stages of life, there can be both psychological and physical reminders of exposure to a hostile environment. For example, suffering from frostbite injuries received during service in cold conditions in Eastern Europe can manifest and bring back both physical pain and also agonizing memories of living in freezing conditions.

Case example

Mr. J is a veteran of the Korean War. He lived in a prisoner-of-war camp for several months and experienced exposure to both extremely hot and cold weather. The food he was served came at unpredictable times and was not familiar to him; he was surrounded by rats, cockroaches, and other insects. He had to live without knowing much about the status of the war, his buddies, or

his family back home. Fifty years later, as his death came within weeks, Mr. J began hoarding his medication. He would tuck the pain medication that his wife gave him inside his cheek and then later grip the pills in his hand until he could hide them inside his bedside drawer. This continued until he was too weak to access his drawer. His hospice nurse, who came to his house to assess his spouse's report of increased grimacing and pain, found a tight fist holding two days' worth of pain medicine. Mrs. J stated she never noticed her husband hoard anything before, but now as he became increasingly debilitated and dependent on others for his care, some of the survival tactics that he learned as a POW returned.

Trauma from exposure to violence

Military experience can include witnessing, committing, or receiving violent acts. Violence can be in the form of physical violence or killing, but also as other atrocities such as sexual assault or mutilation. Breslau and Davis (1987) found that between 73% and 93% of Vietnam veterans experienced “ ‘enemy fire,’ ‘buddy killed in action,’ ‘combat patrol and other dangerous missions,’ ‘surrounded by the enemy,’ and ‘witnessed atrocities’ ” (p. 581). It is important to note that violent acts occur not only during wartime combat between enemy soldiers, but also during peacetime hostilities and between soldiers of the same service unit. Exposure to violence can be powerful enough to have a negative, transgenerational impact on veterans' families. An increase in behavioral disturbances in children of Vietnam War veterans, 15 to 20 years after the veterans' exposure to violence, was noted by Rosenheck and Fontana (1998).

Case example

Mr. P is a veteran of the Vietnam War. While serving in Vietnam, Mr. P was a gunner who had the duty of clearing enemy villages of Viet Cong presence. He left service not knowing how many enemy combatants he had killed nor how many civilian adults and children were in the crossfire. He married, had one son, and divorced. He had frequent nightmares and flashbacks to his time clearing these villages. Being present with his son was at times extremely difficult and painful for him as he would be lost in these memories. He was not always kind to his son as a result, and drinking alcohol seemed to be the easiest form of medication to ease his anxiety. His son was arrested twice for shoplifting and was suspended from school frequently for fighting on the playground. Mr. P and his son lost touch over the years. As Mr. P approached

death, the hospice social worker tried to honor his request to find his son, but to his surprise discovered the son, while trying to hold up a convenience store, had been killed. After informing Mr. P that his son was dead, the veteran held back some tears and never spoke of him again.

Posttraumatic Stress Disorder (PTSD)

The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994), categorizes PTSD as anxiety disorder characterized by a traumatic event where actual or threatened death or physical harm was experienced or witnessed. The DSM-IV lists numerous possible symptoms, such as: recurrent and intrusive thoughts or dreams; avoiding thoughts, feelings, or activities and places that may trigger memories of the trauma; signs of increased arousal (difficulty with sleep, irritable mood, hypervigilance, and strong startle reflex). The symptoms must be present for more than one month to meet criteria for diagnosis, and it needs to cause significant distress or impairment in social functioning.

As most would expect, instances of PTSD are higher in the veteran population than in the civilian population. In the general public, 3.6% of men and 9.7% of women have a lifetime prevalence of PTSD. Vietnam veterans have a 30.9% lifetime prevalence among men and 26% among women. It is estimated that 13.8% of veterans from the Iraq and Afghanistan wars meet criteria for PTSD (Gradus, accessed 2012). However, many more veterans have experienced trauma or feel distress from trauma exposure but do not meet the formal diagnostic criteria for PTSD. PTSD can also be misdiagnosed as another anxiety disorder or as depression.

PTSD can be acute or chronic, and veterans are more likely to experience delayed-onset PTSD than civilians (Andrews, Brewin, Philpott, and Stewart, 2007). It is not uncommon for family members to be unaware that their loved one has PTSD, and to discover it for the first time as the veteran transitions closer to debilitation or death. Symptoms of PTSD may increase as disability increases and coping skills decline (Hamilton and Workman, 1998). When PTSD symptoms have acute manifestation at the end of life, this can be alarming, confusing, and distressing to families. It is important for hospice staff to be prepared to provide education to families about PTSD.

As stated by Feldman and Periyakoil (2006), treatment options for PTSD in a hospice or palliative care setting can be limited by several factors. First, hospice staff may not have trauma experts available to manage the symptoms. Second, if a patient with a prognosis of weeks is experiencing acute-onset

PTSD, there may not be time for pharmacologic intervention to take effect. Third, veterans with PTSD may not have the necessary trust in their medical providers to accept interventions. Likewise, distrust and avoidance behavior can explain why some veterans approach death without any family or friends in their lives. Without trust from the patient or the presence of any family or friends to encourage that trust, the providers must use what Feldman and Periyakoil (2006, p. 217) call “an extremely patient-centered approach,” where the relationship between provider and patient is “egalitarian” and patient control is enhanced.

Case example

Mr. F is a 77-year-old veteran of the Korean War. He never married and lived most of the last 20 years of his life in a small trailer park outside of the city. He refused to see a physician until the owner of the trailer park persuaded him to come to the local VA emergency department to evaluate a very large tumor that was growing on the side of his face. When he checked into the emergency room, Mr. F entered “None” as his next of kin. Mr. F was briefly hospitalized, but was released to a nursing facility once he made it clear he would not accept any treatment for this rapidly growing, malignant tumor. It was not easy to get Mr. F to agree to be admitted to the nursing home, and he only did so after the trailer park owner told him he could not come back to live alone in a trailer.

Mr. F was fairly irritable with staff at the nursing home, but overall adjusted to his new surroundings. However, staff noted many unusual behaviors. At specific hours of the day Mr. F would get out of bed, look under his bed, look in his closet, look out the window, and down the hallway. Staff had to announce themselves loudly from the doorway before entering, because one time he took a swing at a nurse who was near his bed when he woke up. Staff and other residents became very concerned when Mr. F began screaming at different intervals during the day and even occasionally at night. Eventually a nurse realized he was screaming whenever a plane flew overhead. Although by this point Mr. F was too delirious to confirm this, staff assumed the sound of the planes triggered flashbacks. A simple intervention of providing him earplugs helped block that trigger, although staff had to continue to be cautious when approaching him for any physical care. Even in his last hours of life he was strong and would occasionally swing or swat at those trying to bathe him.

LIFE REVIEW WHEN TRAUMA IS A PART OF THE STORY

Life review is the process of self-reflection and evaluation of a life that, in the context of a hospice setting, is approaching the end. Life review can be conducted internally and in silence, or can be shared with families, clinical staff, or caregivers. It can be a transformative experience for some, helping them to reach a point of “forgiveness for self and others” (Jenko, Gonzalez, and Seymour, 2007, p. 165). Butler (1963) described life review as “a naturally occurring, universal mental process characterized by the progressive return to consciousness of past experiences, and, particularly, the resurgence of unresolved conflicts; simultaneously, and normally, these revived experiences and conflicts can be surveyed and reintegrated” (p. 66). When trauma (and associated feelings of guilt, shame, and regret) is a part of the life story, however, the life review process can be excruciatingly painful. It can also be difficult if not impossible to reintegrate the trauma experience(s).

Approaching veterans about life review

Just as no one person is the same as another, no veteran is the same as another veteran. However, it can be helpful to consider some similar experiences that many veterans share. For some, their time in the military was memorable but has not really impacted their post-service life. For others, time in the military was a key highlight in their lives and perhaps the most significant contribution made in their lifetime. Veterans have all had some degree of military training that likely included training related to controlling one’s emotions and emphasizing a stoic response to pain or suffering (Hoyt, Rielage, and Williams, 2011). This training can manifest at the end of life, which can result in physical pain being denied and emotional pain being stifled. It is important to remember that suffering may be happening even if there are no outward signs of it.

Veterans may not want to talk about their military experience, perhaps because of the trauma associated with it or perhaps because it is not the most significant piece of their life story. However, others have come to believe or experience that family and friends do not have the interest, or perhaps the fortitude, to hear their story. Other veterans do not want to share their story and risk being judged or rejected for its contents. Simply asking, “I understand you served in the military. What was that experience like for you?” is likely to bring about some sort of response. The response may be indifferent, glowing, or hostile but, more likely than not, the response will be genuine. By bringing up the topic, the process has begun to engage the veteran in his or her story.

The duration of the life review process may be one brief visit or perhaps a few,

but time is unpredictable given the short prognosis and possibility of slipping into delirium or unconsciousness prior to death. It is important for caregivers and staff to engage hospice patients in life review when the opportunity is right, because there may not be a second chance.

Theoretical guidance

In the mental health field, no one theory or model of psychotherapy has been proven to be most effective in the treatment of PTSD (Benish, Imel, and Wampold, 2007; Wampold et al., 2010). However, the opportunity to share about their traumatic experiences has been reported to be helpful by most who experienced trauma (Zatzick et al., 2001). Recently, much attention is being given to the usefulness of Narrative Therapy and Narrative Exposure Therapy in the treatment of PTSD and also to the process of conducting life review (Bohlmeijer, Westerhof, and Emmerick-de Jong, 2008; Korte, Bohlmeijer, Cappelliez, Smit, and Westerhof, 2012; Robjant and Fazel, 2010). Narrative Therapy, as developed by White and Epston (1990), is a type of counseling which helps patients or clients reconstruct and expand their view of their personal history and identity. The theory assumes that people view their lives like a story, and they retain or reject experiences depending on how well they fit with their dominant storyline. As partners, the client and counselor discuss in detail the patient's existing story and then rebuild the story while integrating new alternatives, views, and experiences which have been left out previously.

When working with veterans who are in the last weeks or months of life, it is often not possible to engage them in formal Narrative Therapy or other psychotherapeutic processes that would be done in a counseling office or with a specific curriculum conducted over a set number of weeks. Instead, it can be helpful to borrow certain components of narrative therapy that can be utilized as tools to assist with life review.

1. Realize that life review is not about collecting facts or eyewitness accounts, but understanding the life story from the perspective of the patient (Kropf and Tandy, 1998).
2. To better understand the story, ask questions that are open-ended and may have a hint of wonderment. "I heard you say that many soldiers on the enemy side died because of your work as a gunner. I know this has been on your mind ever since. I was wondering, what thoughts do you have about the people whose lives were actually saved because of that same work?"

3. Be prepared to reflect back to the patient items that sounds like contradictions in their story. “I am a little confused. You said that nothing good came from your time in the service. But you just mentioned how you were able to get closer to your son by teaching him some of the survival techniques you learned from the service. Is that something good that came from your military experience?”
4. Anticipate that some patients will surprise themselves with some memories that they have forgotten or failed to integrate in their life story until now. “You know, I forgot all about that praying I did when I was over there. I remember asking God that if it’s His will for me to stay and fight, then so be it. Back then it seemed like God didn’t hear my prayers. Now I wonder if that was just what He wanted me to be doing.”
5. It is not enough to listen to the life story and ask questions that bring to light forgotten or nonintegrated memories; the counselor should also reflect back to the patient their new story. With healthier patients, this is often done in the form of a letter that summarizes their story with the newly discovered elements incorporated. For a patient at the end of life, a verbal recount is likely the only option.

DEALING WITH INTENSE EMOTIONS AND STORIES

It is not easy to bear witness to the stories of others, particularly when the stories involve violence or tragedy. It can be anguishing to see another suffer and know that this person has been suffering from these experiences for many years. Being present in silence can often be the best way to demonstrate to the veteran that his or her story, no matter how horrific, did not cause the listener to reject him or become so overwhelmed that she could no longer share. The listener should not try to rush the veteran along or quiet the story with well-intended phrases like, “Well, it’s okay now, that happened a long time ago,” when to the veteran it feels like it is happening now and not 50 years ago. It is okay to be silent and to listen; when the story is over, it may be the right time to offer words of reassurance or even forgiveness. “Thank you for sharing that with me. I know that wasn’t easy to talk about. I want you to know that I respect you all the more knowing now what you have carried with you since the war. I’d like to hear more if there is more you want to share.”

Just as the physical effort of caring for someone who is terminally ill can be significant, so too can be the emotional effort. It is important for those who are privileged to listen to a life review that involves trauma to make the effort

to care for themselves. If you have just absorbed a story of high intensity, what do you do with that? Think about it while walking in the sunshine. Release it through prayer or meditation. Share about it with your fellow team members. It is important to have a plan for self-care to strengthen and sustain oneself, because the need to bear witness to more intense stories may come again soon.

WHAT TO HOPE FOR FROM LIFE REVIEW?

Some people say that people die the way they lived. This adage denies the transformative process that can happen at the end of life for many. Providing a veteran with the opportunity to reflect on his or her life can be the key to a transformative experience when life expectancy is very short. Life review can be intense and frightening for the veteran and, sometimes, for the one privileged to bear witness to the veteran's story. What can be gained from doing this when life expectancy is short? For the veteran, the sharing of the story in itself can be cathartic. From sharing, reflecting, and learning new insights, some may come to a place of forgiveness (of themselves or others) or internal rest that they did not experience before. For the family, this can be an opportunity to learn more about their loved one, and can give the family new insights into not only the veteran but also how his or her life experiences affected the entire family. For the bedside clinician, what can be gained is the feeling of privilege and honor that comes from being trusted with these stories and facilitating an experience of support and acceptance before the veteran dies.

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