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Assessment and Treatment Considerations for Post Traumatic Stress Disorder at End of Life

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Abstract

Post traumatic stress disorder (PTSD) may first emerge, reemerge, or worsen as individuals approach end of life and may complicate the dying process. Unfortunately, lack of awareness of the occurrence and/or manifestation of PTSD at end of life can lead to PTSD going unaddressed. Even if PTSD is properly diagnosed, traditional evidence-based trauma-focused treatments may not be feasible or advisable with this group as many patients at end of life often lack the physical and mental stamina to participate in traditional psychotherapy. This article reviews the clinical and empirical literature on PTSD at end of life, as well as discusses assessment and psychotherapy treatment issues with this neglected population. In addition, it expands on the current reviews of this literature^{1–3} by extrapolating results from nontraditional treatment approaches with other patient populations. Elements of these approaches with patients sharing similar characteristics and/or comorbidities with patients with PTSD at end of life may provide additional benefits for the latter population. Clinical implications and suggestions for interdisciplinary care providers are provided.

Keywords

post traumatic stress disorder; PTSD; end of life; hospice; palliative care; psychotherapy

Although trauma and post traumatic stress disorder (PTSD) have received much empirical investigation in children, adolescents, young adults, and middle-aged individuals, much less attention has been paid to trauma and its negative mental health consequences in older adulthood.⁴ In particular, there is a relative dearth of research on assessment and treatment

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of PTSD in end of life care settings. This death is problematic because PTSD may interfere with “making meaning of one’s existence while preparing for death.”⁵ Patients with significant psychological distress at end of life often display difficulties making treatment decisions, obtaining closure with family and friends, tolerating pain, and engaging in social relationships.⁶

The present article reviews the literature on PTSD in individuals at the end of life. Previous reviews of PTSD at end of life^{1–3} have identified difficulties in assessing and treating this population and have provided some suggestions for providers. This article expands on these previous reviews by providing a more in-depth discussion of the complications to assessment and treatment added by medical and cognitive comorbidities. It then extrapolates from results of treatments from these other patient populations to suggest variations in traditional psychotherapies and/or additional techniques that may benefit patients also struggling with PTSD at end of life. Clinical implications and suggestions for providers are discussed.

Post Traumatic Stress Disorder: Causes and Sequelae

Post traumatic stress disorder was first added to the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* in 1980.⁷ According to *DSM-5*,⁸ PTSD can occur after individuals experience, witness, or learn about traumatic events involving threats of death, serious injury, or sexual violation. Symptoms of the disorder fall into 4 categories: reexperiencing (e.g., nightmares, flashbacks), avoiding situations that serve as reminders of the traumatic event(s), negative changes in thoughts and feelings, and trauma-related arousal and reactivity, and cause significant distress and impairment in functioning. Recent investigations of community-dwelling adults generally indicate that older adults report fewer traumatic events and related psychiatric symptoms than do younger individuals. For example, the prevalence of past-year PTSD was significantly higher for younger (4.3%) and middle-aged (5.2%) adults compared with older adults (2.6%).⁹ Although a systematic review concluded that delayed-onset PTSD is unusual, especially in the absence of prior symptoms,¹⁰ PTSD can first appear or worsen in old age.^{11,12} In particular, symptoms may emerge or reemerge as individuals approach death, possibly due to challenges that arise during the aging process (e.g., increased health problems, cognitive decline, loss of loved ones).^{13,14} In addition, thoughts about impending mortality may trigger reminders of traumatic experiences and memories.^{12,15} Serious medical diagnoses^{16,17} or treatments² can also lead to an appearance or reappearance of symptoms.

Most studies of older adult trauma survivors are cross-sectional, and few investigations of trauma survivors have longitudinally followed individuals into older adulthood. Most of what is known about the course of PTSD symptoms across the life span primarily comes from research on combat veterans or former prisoners of war or is suggested in case descriptions. In these samples, multiple potential trajectories have been reported: remission, temporal stability of symptoms, subclinical symptoms becoming full and chronic PTSD, delayed-onset possibly after several decades postwar, or waxing and waning of symptoms.

Assessing PTSD at End of Life

There are many reliable and valid approaches to assessing PTSD.²¹ Description of specific instruments, such as the PTSD Checklist for *DSM-5*,²² can be found at www.ptsd.va.gov. In general, structured assessment tools (both clinician-administered and self-report) are the preferred method for assessing symptoms and making a diagnosis of PTSD. However, while these instruments have demonstrated good reliability and validity in the general population, and some have been demonstrated as valid for use with older adults,⁴ they are not validated for use at end of life. Many patients at end of life may not have the stamina to complete a lengthy formal assessment¹⁹ but may be able to complete the assessment if broken into smaller sessions or if brief instruments are utilized. For example, PTSD screening tools such as the Primary Care PTSD Screen for *DSM-5*²³ may be useful. Post traumatic stress disorder is rarely the presenting complaint of patients at end of life.¹⁶ Older patients may be uncomfortable expressing their emotions²⁴ and may focus on somatic symptoms.^{2,6} Patients and care providers may also have difficulties connecting current psychological distress to traumatic experiences that occurred prior to PTSD becoming a recognized disorder.^{4,25} Similarly, behavioral symptoms (e.g., agitation, irritability) may not be accurately attributed to the impact of prior traumatic experiences.²⁶ In addition, psychological distress at the end of life may be considered to be a normal part of the death process.²⁴

Cognitive conditions may coexist with, or be diagnosed instead of, PTSD.² For example, delirium is very common in patients in end of life settings.^{27,28} Although studies on the comorbidity of the PTSD and delirium are lacking, it may be difficult for care providers to differentiate symptoms of PTSD (e.g., paranoia, hallucinations).^{6,11}

More research has been conducted on the relationship between PTSD and dementia, with results indicating that the former is a risk factor for the latter.^{29,30} Comorbidity of the two conditions can create additional difficulties. Patients may display symptoms of psychosis³¹ or experience traumatic flashbacks.¹² Cognitive impairment may also impede patients' ability to inhibit or control their PTSD-related symptoms, resulting in more impulse control difficulties and aggressive behaviors.³²

One reason that PTSD may be mistaken for other conditions at the end of life is that patients (especially those with cognitive impairment) may not be able to describe the trauma.² This inability may preclude their ability to recognize, understand, or describe emotional experiences, leaving only observable, external symptoms (e.g., nightmares, outbursts) as the basis for diagnoses,^{33,34} many of which may appear similar to other conditions.^{1,33,34} Current assessment tools may be inadequate for diagnosing PTSD in individuals with severe cognitive impairment or poor verbal communication abilities.¹³ However, a validated assessment measure of traumatic history and symptoms for patients unable to provide this information themselves has not yet been developed.²

Pain (common at end of life) can also complicate the recognition and treatment of PTSD at the end of life by co-occurring with, exacerbating and/or being diagnosed instead of, PTSD. For example, pain has a bidirectional relationship with PTSD. Trauma may affect the extent of pain that patients report.² In addition, patients with pain may experience more symptoms

of PTSD than do those without pain.¹¹ Similarly, pain intensity, pain anxiety, and the extent to which pain interferes with activity predict PTSD symptomatology.³⁵ One reason for the connection between pain and PTSD is that pain may serve as a reminder of the traumatic experiences.³⁶

In addition to these comorbidities, a wide range of other possible comorbidities is possible including insomnia, drug and alcohol dependence, and advanced chronic comorbidities, all of which should be considered in any comprehensive assessment approach.

The ability to accurately diagnose PTSD is critical not only for proper understanding of patients' presentation and symptoms but also for treatment. If care providers do not recognize that behavioral symptoms often result from PTSD, they may blame patients for disruptive or aggressive behaviors^{32,37} and fail to reduce the presence of triggers leading to these behaviors.²⁶ Medications rather than psychosocial or behavioral interventions may be prescribed, when the latter might be more beneficial to the patients.¹

Given the difficulties assessing PTSD among this population, it is critical for providers to be aware that PTSD may first emerge or worsen toward end of life and that its manifestation will vary, depending on the psychiatric and medical health of the patient. Patients need to be assessed for a history of traumatic experiences.^{3,4} However, if patients are unable or unwilling to provide this information, providers may require alternative methods of obtaining it (e.g., speaking with family members, reviewing medical charts).⁴ In addition, current *DSM* criteria may need to be augmented with additional assessment strategies when diagnosing psychiatric conditions in those having severe medical illness and/or the cognitive impairment that is frequently experienced at end of life.^{6,24} In fact, some have proposed revising the PTSD diagnostic criteria for patients at the end of life, as the symptom presentation may differ for this population, for example, acting out, akin to the presentation of the disorder in children.³⁷ In sum, clinicians will want to remain alert for identifying and evaluating PTSD symptoms at the end of life—particularly as patients may not identify them as such. Assessment may be complicated by comorbid dementia, delirium, and pain. Despite these complications, a skilled clinician can weigh the etiologies of various symptoms in determining a diagnosis.¹³ Focusing on intrusive and discomforting memories, thoughts, and dreams of trauma may be especially critical.

Treating PTSD at End of Life

General Considerations

Treatment of PTSD generally falls under the purview of professionals with mental health training. However, because of the interdisciplinary nature of end of life care settings, providers without specialized psychological training should be informed about the ways in which PTSD manifests and may impact care needs. Some strategies (e.g., allowing patients to express emotions)³⁸ apply to psychological distress in general. Others pertain more specifically to PTSD. For example, being fully present with patients,³⁹ helping patients feel in control,¹ listening to and validating painful traumatic events,³⁸ focusing on strengths and resilience,³¹ and avoiding triggers of the traumatic events (e.g., restraints, loud noises).^{26,32,40} In addition to the symptoms themselves, secondary difficulties may interfere with the

dying process. For example, many patients with PTSD may have strained social relationships and reduced social and caregiver support.^{1,15} In addition, PTSD is often associated with negative mood states, difficulty trusting authority figures, skepticism of medical advice, and problematic interactions with medical providers.^{1,15,38} Being aware of these common sequelae of PTSD can enable care providers to understand, discuss, and work to address patients' behavior and concerns.

In addition, pharmacotherapy plays an important role in the management of its symptoms,⁴¹ especially among patients for whom there are challenges and limitations to implementing psychotherapeutic techniques¹⁵ and for those who have cognitive and medical comorbidities.^{1,2}

Psychoeducation

Regardless of the treatment modality used to treat the PTSD symptoms, psychoeducation is recommended to help patients understand PTSD and how it might be triggered or exacerbated at the end of life.¹ For example, care providers can inform patients about the possibility of increases in symptoms of PTSD after changes in medical status or before medical procedures.^{31,42} This education, along with suggested resources, can also be provided to caregivers and family members to help them better understand and take care of the patients.¹

Psychotherapy

Psychotherapy and psychopharmacology (alone or in combination) have been found to be effective in treating PTSD in younger community residing populations.^{41,43,44}

Evidence-Based Psychotherapies

Manualized trauma-focused psychotherapies are the treatment of choice for PTSD.⁴³ Specifically, three evidence-based practices (EBPs) have demonstrated much empirical support. Prolonged exposure (PE) exposes patients to memories of traumatic events through repeated recounting of their details (imaginal exposure) and/or to trauma-related situations (in vivo exposure).⁴⁵ Cognitive processing therapy (CPT) encourages patients to examine and challenge unrealistic and unproductive thinking patterns related to trauma.⁴⁶ Eye movement desensitization and reprocessing (EMDR) attempts to integrate traumatic memories and associated stimuli. Patients recall trauma-related while receiving one of several types of bilateral sensory input (e.g., side-to-side eye movements).⁴⁷ Each treatment is further described in the corresponding referenced manuals. The majority of studies examining the efficacy of treatments of PTSD have been conducted with younger-to middle-aged adults. Very little research on PTSD has been done with older individuals, particularly those 85 or older or with cognitive impairment,⁴⁸ and virtually none with individuals at end of life, largely due to the difficulty of conducting randomized controlled trials with this population.⁴⁹

Despite their demonstrated efficacy, these evidence-based treatments may be unfeasible, unwise, or unnecessary for use with individuals nearing end of life. Most trauma-focused therapies include eight to sixteen sessions, which may be feasible for individuals with

terminal diseases who have months remaining and have sufficient energy, but may be too taxing for individuals with limited mental and/or physical stamina.^{2,3} In addition, trauma-focused therapies necessitate individuals coming into contact with thoughts, emotions, and memories of traumatic experiences. Although beneficial in the long-term, these EBPs often increase distress and arousal in the short term.^{2,50,51} For patients at the end of life, who are unlikely to experience the subsequent decrease in distress and symptoms,^{2,3} the treatments are in direct contradiction to the goal of palliation of symptoms. Another consideration for individuals in institutional settings at the end of life is that hospital and some end of life care settings frequently lack the privacy conducive to therapy.^{52,53}

Fortunately, researchers have begun to investigate the benefits of modified or alternative therapeutic approaches that have been used in working with this population. The technique and benefits of each approach will briefly be discussed.

Alternative Therapeutic Approaches

Modified Cognitive Behavioral Therapy

Although some aspects of cognitive behavioral therapy (CBT) may be helpful for hospice patients having anxiety and depression,⁵⁴ CBT presents challenges for patients at end of life. For example, challenging negative thoughts would need to consider that many of the negative thoughts may be realistic reflections of patients' terminal situations.⁵⁵ Furthermore, due to advanced medical or physical conditions, patients may not be able to make changes to reach goals specified in therapy.⁵⁵ Finally, even if CBT were effective for PTSD at the end of life, not all patients are willing to participate, perhaps due to a desire to avoid painful or triggering topics.⁵⁶

There is some indirect evidence that CBT may benefit the terminally ill having PTSD. Although not tested exclusively at the end of life, CBT is effective with many patients with PTSD⁵⁷ and commonly co-occurring conditions, such as pain.⁵⁸ With respect to end of life, CBT techniques have demonstrated efficacy^{35,57-59} in the treatment of emotional and behavioral symptoms.⁴⁹ However, modifications (e.g., less discussion of future goals) may be required to better suit the specific population of patients with PTSD at the end of life.

Modified EMDR

Modifications to traditional EMDR may benefit terminally ill patients, even those having cognitive impairment or dementia.² One such modification is "on-the-spot-EMDR" for patients with PTSD and dementia.⁶⁰ In this technique, each session is treated as though it were the first (e.g., therapists reintroduce themselves). In addition, care providers attempt to understand whether behavioral symptoms (e.g., screaming) represent traumatic memories (e.g., flashbacks) and to help the patients feel safe. This approach has resulted in reduced emotional difficulties and fewer behavioral outbursts. Due to the relationship between dementia and PTSD,²⁹ studies demonstrating the effectiveness of modified EMDR for individuals PTSD and intellectual disabilities^{33,34} may have relevance to individuals having dementia or cognitive impairment at the end of life. For example, instructions and methods have been adapted (e.g., more visual cues) to be consistent with patients' cognitive and

emotional abilities.^{33,34} This approach has demonstrated encouraging results, with symptoms of both PTSD and co-occurring conditions decreasing in as few as two sessions and lasting up until the last assessment point at two-and-a-half years posttreatment. Although not conducted with patients at the end of life, the results suggest that these modifications may also benefit that population.

Stepwise Psychosocial Palliative Care Model

The primary focus of the stepwise psychosocial palliative care model¹⁵ is quality of life. In the first step, caregivers provide practical assistance and social support to improve patients' immediate well-being (e.g., assisting with funeral arrangements, reestablishing contact with loved ones). In the second step, therapists offer psychoeducation about PTSD symptoms and coping skills (e.g., techniques for communication with health-care providers, acceptance strategies) to cope with them. In the third step, patients confront and process the traumatic memories, altering the procedures of existing therapies (e.g., PE, CPT) as needed to adapt to patients' conditions (e.g., shorter sessions). In this approach, therapy progresses to the next step in the 3-stage model only when distress remains and when life expectancy enables the patient to benefit from a higher step. There appears to be clinical support (ie, case examples)¹⁷ for the benefits of this approach; however, to date, research has not yet tested its efficacy or effectiveness.

Life Review Techniques

Life review technique,⁶¹ often used with older individuals, may benefit patients with PTSD at the end of life by integrating traumatic experiences into complete narratives of their lives. Randomized trials demonstrate the success of life review interventions for depression,⁶² and other studies indicate its benefit at the end of life.⁶² Single-case studies describe the use of life review for PTSD, but there are no reports of life review for older adults with PTSD at the end of life.

Despite its benefits, life review may not be feasible for many end of life patients, largely due to the initial increase in distress.⁶³ Although effective when it promotes greater integration, self-acceptance, and positive growth, life review can also increase despair and hopelessness.^{1,12} Furthermore, avoidance of traumatic memories, due to the painful emotions they often elicit, may interfere with the life review process.^{3,17} In addition, although the intervention may highlight areas of desired change, many patients will lack the strength or longevity to evince these changes. Similarly, because many individuals will be unable to make direct reparations for their actions, life review may be contraindicated.⁶¹

Other approaches that draw from life review are described in the literature for use at the end of life. Meaning-centered psychotherapy,⁶⁴ a therapeutic strategy similar to life review, aimed at helping individuals retain a sense of meaning and purpose to their lives as they approach death, has shown promising results for individuals at the end of life. In one study, patients with advanced cancer evidenced less hopelessness and desire for death than did those in a support group.⁶⁴ This approach has more recently been adapted for patients with very little time remaining in their lives (e.g., only three sessions conducted at patient's bedside, focusing on the key points at the beginning of sessions).⁵⁵

Dignity therapy, a variation in meaning-centered therapy, asks patients nearing end of life reflect on their lives and their hopes for their legacy.⁶⁵ Results have been promising, with patients reporting feeling more helped by the therapy, with improved quality of life and sense of dignity than those receiving other interventions.^{65,66}

Spiritually Oriented Psychotherapy

One component of integrating experiences into a cohesive narrative (ie, life review technique) for individuals is reconciling inconsistent actions and values. This attempt at reconciliation can spur moral or spiritual crises at the end of life, when many individuals first become aware of their guilt and desire for forgiveness, or these feelings have increased salience.⁶⁷ Helping patients with these crises is important, given the relationships among purpose, meaning, regret, and suicidal ideation among many individuals at the end of life.⁶⁸ Spirituality is recognized as an important element of patient-oriented care and means different things to different people.⁶⁹ Because of the complexity of spiritual crises, both clergy and trained mental health professionals may be involved in spiritually oriented treatment,^{67,70} to help individuals find meaning in their lives.⁷¹

Spiritual well-being has been found to be more strongly related to despair at the end of life than is either depression or hopelessness.⁶⁴ In addition, religious rituals (e.g., confession ceremonies) can help in the healing process from PTSD.³⁷ Finally, due to the relationship between death anxiety and PTSD, discussions surrounding death (which often contain a spiritual component) may be beneficial in the therapeutic process for PTSD.³⁶

Complementary and Alternative Approaches

Patients with PTSD, who are either unwilling to participate in traditional treatment of PTSD or who do not experience symptom relief as a result, often seek complementary and alternative medicine (CAM) techniques, now referred to as complementary and integrative health techniques.⁷² Given the limitations of the use of traditional trauma-focused therapies at the end of life, CAM interventions may be especially helpful with this population.²⁴ Although CAM approaches appear to have promise for this population, care providers need to be cognizant that some treatments (e.g., massage, acupuncture) may serve as triggers for individuals struggling with PTSD. For example, physical contact may conjure up memories of past trauma for survivors of sexual assault.²⁶

Medication

Psychotherapy is the recommended first-line approach to the treatment of PTSD.⁴³ Nevertheless, pharmacotherapy plays an important role in the management of its symptoms,⁴¹ especially among patients for whom there are challenges and limitations to implementing psychotherapeutic techniques¹⁵ and for those who have cognitive and medical comorbidities.² Naturally, the medications prescribed will be impacted by medical and psychosocial variables.

In making a choice about medications to prescribe, the provider must consider life expectancy and specific symptoms. For example, although antidepressants have demonstrated the greatest efficacy in treating PTSD symptoms,⁴¹ rapid-acting medications

(e.g., short-acting benzodiazepines or neuroleptics) may be preferable.¹ Furthermore, some psychotropic medications are contraindicated for use with older adults⁷³ or are not recommended in combination with other frequently used medications in hospice or palliative care settings.¹⁶ In addition, oral-administered medications may not be an option for many patients.³⁷ Finally, some medications increase the risk of additional medical complications (e.g., falls, gastrointestinal bleeding).²⁴

Despite their benefits, medications rarely eliminate distress.¹⁵ Furthermore, some patients reject medications. For example, many veterans equate medication with weakness, fear that the sleep-inducing side effects will trigger nightmares, or worry that they may become addicted to medication.³⁷

Clinical Implications

In order to effectively treat PTSD at the end of life, the disorder must be accurately recognized and assessed. Awareness of the phenomenon and screening or assessment is an important first step. Following accurate assessment of PTSD, end of life treatment teams must be familiar with approaches that are likely to be both feasible and efficacious with this population and modify them as needed to serve the individual patients. As outlined in this review, a number of treatment approaches may be useful, and a stepped care approach may be beneficial. Treatment is likely to involve a multiprofessional, multimodal approach that is tailored to the individual.

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