Case Discussions in Palliative Medicine

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Posttraumatic Stress Disorder at the End of Life

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CASE

A 61-YEAR-OLD Caucasian, unmarried man was referred for inpatient hospice care. He was diagnosed with congestive heart failure and had a history of type 2 diabetes. The patient was referred for hospice care because of increasing difficulties caring for himself, as evidenced by two recent falls. He denied any psychiatric or substance abuse history. After admission, he began experiencing difficulty sleeping because of nightmares about being stalked or attacked, disturbing thoughts and memories that he could not put out of his mind, mild paranoia, vivid hallucination-like episodes, and intense anxiety alternating with periods of having “no feelings at all.” Moreover, he became increasingly confrontational with staff. He was a veteran of the Vietnam War. He had been drafted into the Army and served as a field medic. When asked directly about his wartime experience, he indicated that he believed the present symptoms were connected to it but changed the subject if asked to elaborate in any detail. The staff struggled with how best to care for this patient, who died 14 days after admission.

DISCUSSION

Psychiatric symptoms are highly prevalent in patients near the end of life. The challenge to the clinician is to make an accurate diagnosis and treatment plan. In the present case, upon observing the patient’s confrontational and suspicious behavior, nursing staff initially reported that he appeared “anxious” and “confused.” This behavior, in combination with the hallucination-like episodes and further heightened affect that he displayed thereafter, easily could have been mistaken for delirium. The risk is to liberally prescribe anxiolytics (such as lorazepam) and neuroleptics (such as haloperidol) for terminal delirium without doing the often intense and frustrating work of digging a bit deeper.

Upon closer examination, it became clear that the patient suffered from posttraumatic stress disorder (PTSD) with delayed onset originating in his Vietnam combat experience. Although he previously experienced few symptoms, the full PTSD syndrome was triggered when he was informed of his terminal prognosis and enrolled in hospice care. His presentation included nightmares, flashbacks, intrusive trauma memories, emotional numbing, efforts to avoid thinking about the trauma, irritability, and insomnia. Unfortunately, virtually no research addresses PTSD at the end of life. Thus, many questions remain unanswered: How is PTSD usually expressed at the end of life? How is the dying process affected? How can hospice and palliative care providers be of most help to patients suffering from PTSD?

In what follows, we describe the symptoms of PTSD, examine how the disorder may affect the dying process, provide a set of screening questions, and discuss treatment options. Although the present patient is a combat veteran, the considerations discussed herein apply equally well to non-veteran populations and patients with PTSD stemming from other traumas.

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RECOGNIZING PTSD

PTSD is a mental disorder characterized by extreme difficulty adjusting to a trauma. The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) defines "trauma" as any event that a person experiences, witnesses, or is confronted with that threatens death or serious injury, or is a threat to the physical integrity of oneself or others. Among Americans, estimates of lifetime prevalence for such events range from 39% to 84%. Events that may cause PTSD include motor vehicle accidents, natural disasters, terrorist attacks, combat exposure, domestic violence, childhood abuse, and sexual assault, among others.

Although most traumas do not lead to PTSD, approximately 25% of people who experience a trauma develop the disorder, with females at greater risk than males. Unfortunately, research indicates that medical providers often fail to recognize and diagnose PTSD when appropriate, instead identifying related symptoms of depression and anxiety. While PTSD can superficially manifest as either of these conditions and can overlap with them, it is a distinct syndrome.

PTSD is comprised of three clusters of symptoms (Table 1). Almost pathognomonic of PTSD are reexperiencing symptoms such as repetitive disturbing memories, nightmares, and hallucination-like flashbacks. The second cluster, avoidance symptoms, consists of attempts to avoid reminders of the trauma. Avoidance of objects, places, and people can lead to significant functional impairment. Moreover, individuals may attempt to suppress trauma-related memories and emotions, sometimes leading to amnesia for aspects of the trauma or a sense of being emotionally "numb." The third cluster consists of hyperarousal symptoms, commonly evidenced by

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<tr>
<th>TABLE 1. DSM-IV-TR Diagnostic Criteria for Posttraumatic Stress Disorder</th>
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<td>A. The person has been exposed to a traumatic event in which both of the following were present:</td>
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<td>(1) The person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others</td>
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<td>(2) The person’s response involved intense fear, helplessness, or horror. Note: In children, this may be expressed instead by disorganized or agitated behavior.</td>
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<td>B. The traumatic event is persistently reexperienced in one (or more) of the following ways:</td>
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<td>(1) Recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions. Note: In young children, repetitive play may occur in which themes or aspects of the trauma are expressed.</td>
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<td>(2) Recurrent distressing dreams of the event. Note: In children, there may be frightening dreams without recognizable content.</td>
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<td>(3) Acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated). Note: In young children, trauma-specific reenactment may occur.</td>
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<td>(4) Intense psychologic distress as exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.</td>
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<td>(5) Physiologic reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.</td>
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<td>C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:</td>
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<td>(1) Efforts to avoid thoughts, feelings, or conversations associated with the trauma.</td>
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<td>(2) Efforts to avoid activities, places, or people that arouse recollections of the trauma.</td>
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<td>(3) Inability to recall an important aspect of the trauma.</td>
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<td>(4) Markedly diminished interest or participation in significant activities.</td>
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<td>(5) Feeling of detachment or estrangement from others.</td>
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<td>(6) Restricted range of affect (e.g., unable to have loving feelings).</td>
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<td>(7) Sense of a foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span).</td>
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<td>D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:</td>
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<td>(1) Difficulty falling or staying asleep.</td>
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<td>(2) Irritability or outbursts of anger.</td>
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<td>(3) Difficulty concentrating.</td>
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<td>(4) Hypervigilance.</td>
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<td>(5) Exaggerated startle response.</td>
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<td>E. Duration of the disturbance (symptoms in Criteria B, C, and D) is more than 1 month.</td>
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<tr>
<td>F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.</td>
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hypervigilance, irritability, exaggerated startle response, and insomnia. Additionally, psychosocial issues such as depression, general anxiety, substance abuse, distrust in authority, and survivor guilt are often comorbid with PTSD.

If PTSD is suspected based on behavior or history, the most effective way of screening for the disorder is to ask patients about their present symptoms and past experiences. It may be especially important to assess for PTSD when patients fall into high-risk groups such as combat veterans, victims or witnesses of terrorism or violent crime, and survivors of natural disaster. Although it may be painful for some patients to speak in detail about their traumas, a study involving interviews of trauma survivors found that most individuals felt supported by the opportunity to speak about their experiences.9 Table 2 contains four questions useful for rapid PTSD screening.10

In addition to the assessment of PTSD itself, screen for associated mental health conditions. Although PTSD often presents in isolation, the addition of common comorbidities such as depression, anxiety, and substance abuse complicates the psychiatric picture and may influence choice of treatment approach. Suicide risk is also an important concern; this should be assessed and, if present, steps should be taken to keep the patient safe.

PTSD AND THE DYING PROCESS

Virtually no research addresses the intersection of PTSD and terminal illness. Although patients with cancer clearly have a higher incidence of PTSD than the general population,12–14 it is unclear to what extent terminal illness is itself the instigating trauma versus a trigger for preexisting PTSD.15

In our experience, PTSD can complicate the dying process in several ways. First, the threat to life inherent in terminal illness may mimic the original trauma, exacerbating previously mild PTSD symptomatology and leading to significant distress. Second, when key memories are trauma-related, the normal process of life review can lead to intense anxiety, sadness, guilt, or anger. Third, because avoidance symptoms are central to the diagnosis, individuals with PTSD tend to cope by avoiding or ignoring problems.17–19 This can lead to poor medical adherence20 and may render direct, problem-focused doctor-patient communication difficult. Fourth, distrust in authority can lead to excessive questioning of providers’ actions as well as refusal of care. And last, patients with PTSD may lack caregivers because of a history of social isolation and avoidance.

TREATMENT OF PTSD AT THE END OF LIFE

In this section, we offer suggestions regarding management of PTSD at the end of life. Although pharmacologic and psychological strategies are discussed separately, treatment ideally should combine these approaches.

Pharmacologic management

Specific treatment goals in hospice and palliative care settings should include reduction of frequency and intensity of specific PTSD symptoms, as well as alleviation of any associated anxiety and other symptoms that may mitigate quality of life. Therapeutic strategy is determined by estimated life expectancy, acuity and nature of symptoms, as well as anticipated drug side effects.

Two major classes of drugs effective in palliating PTSD in terminally ill patients are selective serotonin reuptake inhibitors (SSRIs) and tricyclic antidepressants (TCAs).21,22 TCAs are thought to alleviate intrusive symptoms as well as anxious and depressed affect. If TCAs are used, consider imipramine or desipramine in order to minimize the anticholinergic side effects of such medications. SSRIs are thought to alleviate the avoidance and numbing symptoms of PTSD.23 SSRIs, pre-
scribed as monotherapy or in combination with benzodiazepines, are especially effective in pa-
tients suffering from anxiety and panic symp-
toms.24 Hyperarousal symptoms related to the
initiation of SSRI therapy may respond best to an
initial combination of SSRIs and benzodi-
azepines. Consideration may be given to taper-
ing off benzodiazepines after the first few weeks.

A limitation of both SSRIs and TCAs is the de-
layed onset of their effects; as a general rule, a full
therapeutic effect is not noted for four or more
weeks after initial dose. Patients with expected
life spans of months to years may respond well
to ongoing psychotherapy in combination with
medications like SSRIs and benzodi-
azepines. Consideration may be given to tapering
off benzodiazepines after the first few weeks.

Other classes of drugs have also been used to
treat PTSD, though none of these presently are
Food and Drug Administration (FDA) approved
for this purpose.25 For instance, some of the
symptoms of PTSD are thought to be related to
central nervous system adrenergic hyperarousal,
and it has been suggested that adrenergic recep-
tor-blockers such as clonidine could be effective
in treating PTSD.26 Lithium, anticonvulsants, and
clonidine are all thought to alleviate intrusive
symptoms.27 Because clonidine is available as a
transdermal patch, it may be especially useful in
terminally ill patients who have lost the ability to
swallow, although caution should be used in pa-
tients with low blood pressures. Additionally,
low doses of risperidone are thought to be effec-
tive in treating impulsive aggression and psy-
chosis, though some research suggests that over-
al improvement in PTSD symptoms does not
differ between risperidone and placebo-treated
groups.28 Psychotic episodes associated with
PTSD in patients with advanced illness also can
be alleviated with other atypical antipsychotics
like olanzepine. Consider psychiatric consulta-
tion services (if available) in the management of
such severe symptoms.

**Psychosocial management**

No evidence-based guidelines address the psy-
chosocial management of PTSD at the end of life.
Though effective psychotherapies for PTSD exist,
these approaches often are not possible in hospice
and palliative care settings, given that these set-
tings often lack mental health practitioners with
special expertise in trauma. As such, the respon-
sibility may fall to medical providers. Stein29 sug-

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### Table 3. Psychosocial Checklist

If PTSD is evident, consider the following strategies:

- Adopt a patient-centered approach.
- Take an egalitarian stance with the patient.
- Emphasize the patient’s control over medical decisions.
- Listen and provide emotional support.
- Assess for suicide risk, especially if comorbid depression is present. If necessary, take action to keep the patient safe.
- Educate patient.
  - Provide the patient with information and literature about PTSD.
  - Reassure the patient that he/she is not “going crazy.”
  - Provide information to the patient’s loved ones if permission is given.
- Educate staff.
  - Inform staff of the patient’s PTSD diagnosis.
  - Provide information about PTSD symptoms and how these can interfere with care.
  - Provide reassurance to staff members who have strong emotional reactions to the patient (e.g., sympathy, anger, guilt).
- Develop a set of PTSD resources.
  - Seek out literature on PTSD.
  - Locate mental health professionals with expertise in PTSD.

General considerations for the psychosocial management of PTSD at the end of life. These should be considered in conjunction with pharmacologic options.
gests that physicians are in an excellent position to listen, provide emotional support, normalize patients’ experiences, and encourage patients to enlist help from friends and family. Three additional considerations may be of specific use in hospice and palliative care settings (Table 3).

First, individuals with PTSD often cope through avoidance. Avoidance may be especially prominent at the end of life if patients are socially isolated, lack energy, or become preoccupied by their medical conditions, any of which may hinder doctor–patient communication. Additionally, distrust in authority can cause resistance to medical advice, especially if the physician is perceived as being paternalistic. Of course, if the patient is viewed as being uncooperative or difficult, physicians may respond with their own avoidance, resulting in a vicious cycle of mutual avoidance and escalating hostility.

Given this, we recommend an extremely patient-centered approach. In such an approach, “the doctor works to the patient’s agenda, listening and responding to what the patient says and the doctor-patient relationship is considered egalitarian.” Although most clinicians working in palliative care adopt this stance to some degree, an especially strong emphasis on egalitarianism and patient control often helps to further circumvent suspicion and reduce avoidance.

A second consideration is what education should be provided to the patient, family, and staff. “Psychoeducation” is an effective component of many psychotherapies for PTSD, and it is often helpful in providing patients with information regarding the nature of PTSD and its relation to the dying process. Patients may believe that they are “going crazy,” especially if their terminal prognosis has triggered previously dormant symptoms. Physicians can normalize this experience and reassure the patient that he or she is not “going crazy.” With the patient’s permission, similar information can be provided to family members.

Staff members also should be made aware of the patient’s PTSD diagnosis. Staff members can experience strong emotional reactions to patients with PTSD, especially if these patients are suspicious, resistant, confrontational, or highly distressed. Emotional reactions may include sympathy for the patient’s suffering, anger at the patient’s behavior, and guilt over feeling responsible for the patient’s distress. Education about PTSD can aid staff members in feeling more comfortable providing services to these patients.

Finally, resources are available to help providers struggling with a patient with PTSD. The National Center for PTSD website ([www.ncptsd.va.gov]) provides general information, assessment instruments, and practical treatment guidelines. In addition to such text resources, it may be helpful to identify mental health providers who can offer consultation to physicians and clinical services to patients. Experts in the treatment of PTSD can be found in a variety of professions, including psychiatry, clinical or counseling psychology, social work, and psychiatric nursing. VA hospitals and Vet Centers are good resources for veteran patients, while community mental health centers are good places to begin for nonveterans.

CONCLUSION

According to some estimates, up to 84% of people experience a traumatic event during their lives. Like all of us, these individuals eventually die. Although only a fraction of these people ever develop PTSD, it is essential that providers be able to recognize and palliate PTSD symptoms that may increase suffering at the end of life. It is our hope that future research on this issue will expand, and that clinical awareness of PTSD in hospice and palliative care settings will lead to less suffering and a better quality of life for affected individuals.

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REFERENCES

4. Vrana S, Lauterbach D: Prevalence of traumatic events and post-traumatic psychological symptoms in

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