End of Life Post-Traumatic Stress Disorder (PTSD) in Veterans: Experiences of Rural Hospice Providers

BACKGROUND
Veterans with PTSD at end of life may present unique care challenges.

- Approximately 25% of all Veterans live in rural communities. (1)
- Rural Veterans make up 34% of all Veterans receiving VA healthcare. (1)
- Compared to their urban counterparts, rural Veterans have more severe PTSD symptoms and higher rates of suicide and substance use disorders. (2)
- Rural areas face shortages of mental health providers and less access to specialty mental health care. (2)
- Most rural Veterans live far from VA medical centers (2), making it more likely their end of life care occurs outside VA.

Information about Veterans’ PTSD symptoms at end of life is scarce. There is a critical need to understand how PTSD manifests at end of life and to provide resources, support, and education to rural providers.

METHOD
To understand providers’ experiences caring for Veterans with PTSD at end of life, data were collected from the National Hospice and Palliative Care Organization survey (N = 157) and 10 provider focus groups (in KY, MI, MN, VT, FL; total n=97).

KEY FINDINGS
PTSD symptoms:
- DSM-5 consistent PTSD symptoms at end of life:
  - Nightmares, flashbacks
  - Irritability, difficulty sleeping
  - Guilt, distrust
  - Avoidance of triggering reminders/memories
- Additional trauma-related symptoms observed:
  - Agitation and restlessness
  - Feeling unsafe
  - Isolating or withdrawing
  - Stoicism
  - Resisting care and comfort measures
  - Worsening or hard to treat pain

At end of life, Veterans may wish to:
- Talk about traumatic experiences
- Make meaning
- Reconcile the good with the bad

Rural providers need more support:
- Assessing PTSD symptoms
- Knowing how to respond when a Veteran discloses trauma and trauma-related emotions or negative beliefs

At end of life Veterans with PTSD frequently exhibit “irritability with their caregivers, sleep problems, particularly with disturbed sleep after nightmares, anxiety, guilt, lack of acceptance, and restlessness.”
IMPLICATIONS

1. Rural Veterans at the end of life may experience PTSD and related symptoms that affect their care and their providers’ ability to adequately address their needs.
2. Rural hospice and palliative care providers express a need for more support and resources when providing end of life care for Veterans with PTSD.

NEXT STEPS

1. Develop educational resources and materials about end of life PTSD symptoms to distribute to rural hospice and palliative care providers.
2. Continue to investigate the end of life experiences of rural Veterans and their families, and the needs of rural hospice and palliative care providers caring for Veterans.
3. Assess family members’ and Veterans’ educational needs regarding end of life PTSD.
4. Explore access to, and relevance of, VA-based resources for rural hospice and palliative care organizations.

REFERENCES


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Visit www.ruralhealth.va.gov to learn more.