

# Trauma Informed Care at End of Life: The Role of the Team and Culture

---

Susan Lichtman Maataoui, Ph.D.

Psychologist, Geriatrics

VA Maine Healthcare System

# Definition of Trauma Informed Care

---

Trauma informed care is an organizational approach to care that assumes that everyone who encounters the system might have had a past traumatic event and seeks to ensure practices to avoid re-traumatization. (Fallot & Harris, 2008)

This approach is particularly critical in end-of-life care because past trauma plays a role in how people experience pain, anticipatory grief, and loss in both palliative and hospice care.

# So, why is knowing this important?

---

- The very reason why someone is receiving hospice or palliative services connects them with past trauma-facing a life threatening situation, with minimal control, and the perception that others will be doing things to you against your will or without your knowledge, and that death will be frightening, painful, and chaotic
- Older adults who have experienced trauma are more likely to neglect their own health and care needs at end of life so they are often sicker and less engaged when they are referred to our care
- Pain management may be more difficult for patients at end of life who have diagnosed PTSD, a history of trauma, and/or substance use disorders
- Trauma is often systemic, involving families that are also a part of the care team
- Trauma can be a limiting factor with staff, who have their own feelings, pain, and fears to address



# Ways Trauma Can Complicate End of Life Care

- Living with a life threatening illness, may increase distress and symptoms of PTSD at end of life
- Undiagnosed PTSD or unacknowledged trauma can emerge during declining health and the dying process (LATR)
- Normal life review may result in an increase in PTSD symptoms
- Avoidance symptoms of PTSD may interfere in medical care
- Refusal of care or excessive questioning of providers' actions or distrust of authority may result from past trauma
- Individuals w/ PTSD may experience decreased social support or a lack of caregivers as a result of family discord and avoidance
- Medication management for pain can increase PTSD symptoms

- Physical and emotional safety is the basis of trauma informed care, which is established through **trust** in both providers and systems. Mechanisms for establishing trust include clear and consistent boundaries, clarity of roles and expectations of both the provider and the person receiving services, and consistent follow-through
- The more **choice** an individual has and the more **control** they have over their service experience through a **collaborative** effort with service providers, the more likely it is that the individual will participate in services and the more effective the services may be
- Focusing on an individual's **strengths** and **empowering** them to build on those strengths while developing **stronger coping skills** provides a healthy foundation for individuals to fall back on if and when they stop receiving services.

## 5 Guiding Principles of Trauma Informed Care


SAFETY

CHOICE

COLLABORATION

TRUSTWORTHINESS

EMPOWERMENT



# How do we know if someone has a trauma history?

---

## Engage

Engagement: Ask sensitive questions, get a good history, and collaborate over time with the patient and available collateral contacts (with the patients permission)

## Observe

Observe: Are there signs, such as avoidance of certain types of TV shows, discomfort with one gender of care-givers, refusal or discomfort with personal care offered by staff, anxiety with certain noises or smells

## Dig In

Dig In: Look through the medical record for hints that there may be a history of trauma, or concerns expressed by other providers

## Establish

Establish rapport and trust: Patients may begin to disclose new thoughts/feelings, talk about memories that even family did not know

## Honor

-Honor what you learn: Have these things provide guidance to your team and to how your provide care



# Cultural Competence or Cultural Humility?

---

Hook, Davis, Owen, Worthington and Utsey (2013) conceptualize cultural humility as the “ability to maintain an interpersonal stance that is other-oriented (or open to the other) in relation to aspects of cultural identity that are most important to the [person]” (p. 2).

Becoming culturally competent is a process, not an event; it demands an on-going openness to learning and a willingness to say “I don’t know, but I am listening”

Cultural humility seeks to fix power imbalances in the treatment relationship. The people we work with are the experts in their own life and experience. We know some things, but not all. “One holds power in scientific knowledge, the other holds power in personal history and preferences”.

Cultural humility also involves advocacy- we can become a voice for change and inclusion in care systems by being allies and advocates



# Cultural Mis-steps with Veterans

---

Assuming

Making assumptions about their unique experiences in the military without asking them about their experiences and their views

---

Comparing

Comparing any military experience to a movie

---

Going where you don't belong (yet)

Asking if they killed anyone, or saw someone killed

---

Unwelcome Empathy

Saying you understand

---

Imposing

Trying to impose your values on military experiences or acculturation (i.e., it's more important to take care of themselves than it is to serve others)

---

Jumping to Conclusions

Assuming they have PTSD or Moral Injury because of their experiences, or because of specific symptoms (i.e., have trouble sleeping, or are angry, etc.)

---



# Difficulties of addressing trauma in a hospice setting:

---



- Traditional evidence based therapies (CPT, EP, and EMDR) are not usually the best options in hospice for many reasons:
  - May require too much time and stamina, and cause s/t increases in distress
  - Not designed for on-going trauma and don't address end-of-life concerns
  - Little role for families, who also need care and attention
- Pharmacotherapy is often helpful, but talk therapies have been shown to be equally effective (bonus: no drug interactions!) and medications alone are not enough even if they help reduce symptoms



# Later-Adulthood Trauma Reengagement (LATR)

---

- •Phenomenon occurring in older Veterans who were exposed to stressful war-zone events during early life.
- •These Veterans function well into adulthood, but while facing the challenges of aging (e.g. retirement, illness) begin to reminisce and reengage with combat-related experiences.
- •This reengagement presents an opportunity for post-traumatic growth and meaning making, but can also be a source of distress.
- •The process of trauma reengagement is different than PTSD because avoidance, one of the key symptoms of PTSD, is absent.
- •The process of trauma reengagement is an opportunity to find meaning in one's early life experiences.
  
- Davison et al 2016; Davison et al 2006; Potter et al 2011



# Step-wise Psycho-social Palliative Care: A Patient Centered Approach to Treat PTSD/Trauma in Hospice

---

## Step One

Palliate immediate needs and provide social supports

- Empathy, validation, reassurance
- Practical problem solving
- Psychoeducation for individual, family, and providers to better understand needs and avoid PTSD triggers

## Step Two

Enhance Coping Skills

- Relaxation training, breathing skills, mindfulness, communication skills
- Psychoeducation for family regarding coping skills for PTSD

## Step Three

Treat Specific Trauma Issues

- Modified EMDR and cognitive approaches
- Spiritually based therapy
- Life review/exposure therapy
- Ancillary and Complimentary therapies



# References

- Substance Abuse and Mental Health Services Administration. (2014). Concept of Trauma and Guidance for a Trauma-Informed Care Approach. U.S. Department of Health and Human Services.
- <https://www.apa.org/pi/families/resources/newsletter/2013/08/cultural-humility>
- Feldman, D.B., Sorocco, K.H., and Bratkovich, K.L. (2013). Treatment of posttraumatic stress disorder at the end-of-life: Application of the stepwise psychosocial palliative care model. *Palliative and Supportive Care* (2014), 12, 233–243. doi:10.1017/S1478951513000370
- Harris, M. & Falloot, R. D. (Eds.) (2001). *Using Trauma Theory to Design Service Systems. New Directions for Mental Health Services*. San Francisco: Jossey-Bass.
- <https://socialwork.buffalo.edu/social-research/institutes-centers/institute-on-trauma-and-trauma-informed-care/what-is-trauma-informed-care.html>