1. Define key terms related to trauma-informed care in hospice and palliative care.
2. Understand the prevalence and impact of trauma in the general population.
3. Identify improved patient outcomes when incorporating trauma informed care in your organization.
4. Describe ways trauma informed care in your organization will decrease compassion fatigue and improve retention in your staff.
5. Identify patients/caregivers with underlying post traumatic stress and what to do about it.
Create a Safe Place

Myth - “Not relevant to hospice & palliative care” ... except at the VA
For Example: Sexual Assault in the U.S.

- 300,000 women (90,000 men) raped yearly
  U.S. Dept of Justice/ National Violence Against Women Survey (Tiaden & Theonnes, 2000)

- Nearly 23 million women, 1.7 million men raped or attempted rape in lifetime
  CDC/ 2017 National Intimate Partner and Sexual Violence Survey

- About 1 in 3 women and nearly 1 in 6 men experience “contact sexual violence” in lifetime
  CDC/ National Intimate Partner and Sexual Violence Survey

Worse in Dangerous Environments  Poverty. Prison. War.  
Ex. About 1 in 3 female veterans report an attempted or completed sexual assault during military service  
Brauser (2018)  
(deployed or not)

Psychological Trauma: DSM-5  
American Psychiatric Association (2013)

Events that threaten death, serious injury, or sexual violence e.g., rape, serious accident, life-threatening illness  
(DSM-5)
  - Self or other
  - Directly experienced
  - Personally witnessed
  - Some indirect experiences qualify

Currently -  
We don’t address psychological trauma
PTSD in the DSM-5

Re-Experiencing (one symptom)
• Unwanted upsetting memories
• Nightmares
• Flashbacks
• Emotional distress @ trauma reminders
• Physical reactivity @ trauma reminders

Avoidance (one symptom)
• Trauma-related reminders
• Trauma-related thoughts or feelings

Trauma-Related Arousal/Reactivity (two symptoms)
• Risky or destructive behavior
• Hypervigilance/Heightened startle
• Difficulty concentrating
• Difficulty sleeping
• Irritability or aggression

Lasts 30 days; Distress or Impairment Not due to illness or Rx

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Psychological Trauma

IS COMMON

❖ More than 60% of men, and 50% of women in lifetime (ages 15 -54 years)
❖ More than half of these experience two or more
❖ Doesn’t go away because people get old

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Any Trauma</th>
</tr>
</thead>
<tbody>
<tr>
<td>65-69 years</td>
<td>59.72 %</td>
</tr>
<tr>
<td>70-74 years</td>
<td>64.77 %</td>
</tr>
<tr>
<td>75+ years</td>
<td>75.51 %</td>
</tr>
</tbody>
</table>

Traumas accumulate with increasing age


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**Trauma Exposure is Pathogenic**

- It is a predictor of immediate and lifetime increases in a wide array of mental and physical disorders Breslau et al. (1998); Kessler et al. (1995); Brown (1993); Bremner et al. (1993)
- There are significant psychophysiological effects of trauma exposure even without PTSD
  - Impacts emotion processing, cognition, & mental health (PTSD, anxiety, depression ... )
More than three years after 9/11:
There were multiple areas with significantly lower mean gray matter volume in nonclinical 9/11-exposed adults ($p < .001$, w/control for total grey matter volume).

Ganzel et al., *NeuroImage* (2008)

All implicated in the evaluation and regulation of emotional stimuli in humans

Sources of Trauma

**Being Old**

Accrual, Losses...Life Review

 Reactivation of old trauma memories

- Can reactivate prior PTSD
  - ++ in the context of ill health
- Can result in new PTSD
  - even if the initial trauma didn’t

McLeod (1994); Andrews et al. (2007, 2016) Potter et al. (2013)

**LOSS** - Late Onset Stress Symptomatology

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Sources of Trauma

**Being Sick**

INTENSIVE MEDICAL INTERVENTION CAN BE...

A Trauma!
Sources of Trauma

Critical Care

- Sedation
- Restraint
- Intubation
- Light
- Noise

- > 80% of mechanically-vented ICU patients experience delirium
- Delirium predicts PTSD, cognitive declines, six-month mortality
- Full PTSD in 18 - 34% of ALL patients after ICU care

Granja et al. (2008)

Sources of Trauma

Being Treated for Cancer

PTSD symptoms:

- 20% of patients with early-stage cancer
- 80% of those with recurrent cancer

National Cancer Institute
http://www.cancer.gov/cancertopics/pdq/supportivecare/post-traumatic-stress/HealthProfessional/page1/AllPages/Print; also see Kaas et al. (1993)
**Trauma Symptomatology in Medical Patients**

*From the Research -
PTSD Symptoms predict...*

- Perceived Pain
- Anxiety, Depression, Distrust, Anger
- Avoidance of trauma reminders
  - including medical settings and medical personnel
- Patient-staff collaboration & patient care

Feldman et al. (2014); Otis et al. (2003); Roth et al. (2013); Shemesh et al. (2004)

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**Stress & Trauma at End of Life**

*Old*

- Losses
- Reactivation of trauma memories

*Old + Sick*

- ++ Reactivation of trauma memories
- Intensive medical intervention

*Old + Sick + Dying = Hospice*

- Disease progression
- “Failed” intensive medical intervention

LOCUS of medical trauma-re-activated trauma and PTSD
Trauma Informed Care in Your Organization

SAMHSA’s Concept of a Trauma-Informed Organization:
1) **Realizes** the widespread impact of trauma and understands potential paths for recovery
2) **Recognizes** the signs and symptoms of trauma in clients, families, staff, and others involved with the system
3) **Responds** by fully integrating knowledge about trauma into policies, procedures, and practices
4) **Seeks** to actively resist re-traumatization

www.samhsa.gov/nctic/trauma-interventions

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Trauma Champions

Staff who understand the impact of psychological trauma on the lives of patients and caregivers. When trying to understand a patient’s behavior, the champion will ask, ‘is this related to post-traumatic stress?’ A champion will also think about whether her own behavior is hurtful or insensitive to the needs of a trauma survivor. The champion is there to do an identified job - social worker, spiritual counselor, nurse and aide - but in addition, a champion is there to shine the spotlight on trauma issues.

(Harris and Fallot, 2001)
The Culture of Trauma Informed EOL Care

*Impact on the Organization*

- Increases the quality of services, reducing unnecessary interventions and lowering costs
- Better staff retention
- Potential to improve CAHPS scores
- Opportunity to partnering with SNFs to provide TIC training
- Supports a work/agency culture of sensitivity and respect for diversity and commitment to inclusion
- Complementary with goals of NHPCO’s WHV program/alliance
- A TIC Culture will help avoid policies and procedures that could re-traumatize

Opioid Risk Tool

Questions include:

- Family history of substance abuse
- Personal history of substance abuse
- History of preadolescent sexual abuse
- Presence of psychological disease, e.g.
  - Bipolar
  - Schizophrenia
  - Depression
Concerning Issues

- The Opioid Risk Tool was developed to assess risk of opioid addiction
- Designed to be a self-reporting screening
- Designed for primary care settings
- Designed to assess risk for opioid abuse among individuals prescribed opioids for treatment of chronic pain
- Tool has not been validated with hospice patients
- Potential to cause distress, stigmatize or re-traumatize our hospice patients and their family members

Opioid Risk Assessment Reimagined

- Rational for screening will be clear and transparent
- Any screening done will avoid stigmatizing our patients/family members
- Two simple questions:
  - Do you have concerns about having opiate pain medication in the home?
  - Would a lock box be helpful to control access to these medications?
The Culture of Trauma Informed EOL Care

Impact on the Organization’s Staff

- Reduces potential for compassion fatigue and burn-out [SAMHSA (2014)]
- Protects against secondary trauma [Center for Health Care Strategies (2016)]
- Better staff retention [SAMHSA (2014)]
- Enhances inter-disciplinary and inter-agency communication [Hopper, Bassuk, Olivet (2010)]
- Increases opportunities for learning and skills development [Hopper, Bassuk, Olivet (2010)]
- Increases the quality of services, reducing unnecessary interventions and lowering costs [National Council for Behavioral Health (2013)]
- More cohesive and mutually supportive teams

The Culture of Trauma Informed EOL Care

Impact on Care Facilities

- Enhances communication between Hospice and Long Term Care facilities
- Has the potential to reduce hospitalizations and the use of psychotropic medications
- More effective nonpharmacological responses to patient’s adverse behavioral and psychological symptoms [Feldman (2017); Janssen (2018)]
- §483.25(m) Trauma-informed care:
  - Part of Phase 3 with implementation beginning November 28, 2019
  - “The facility must ensure that residents who are trauma survivors receive culturally competent, trauma informed care in accordance with professional standards of practice and accounting for residents’ experiences and preferences in order to eliminate or mitigate triggers that may cause re-traumatization of the resident.”
The Culture of Trauma Informed EOL Care

Impact on the Patient/Circle of Support

- Identifies patients with trauma histories, ensuring more effective care planning and better outcomes  
  SAMHSA (2015); Feldman (2017); Ganzel (2016)
- Enhances patients’ sense of safety and creates safer physical and emotional environments  
  National Council for Behavioral Health (2013)
- Enhances choice and control  
  National Council for Behavioral Health (2013)
- Reduces the possibility of re-traumatization
- Increased efficacy of hospice interventions and decreases adverse experiences, e.g. psychological crises, isolation, or unwanted hospitalizations  
  Feldman (2017); Ganzel (2015); SAMHSA (2011)
- Improves communication and client/family satisfaction  
  Hopper; Bassuk; Olivet (2010)

Moving Forward

Phases of developing a TIC Culture in your Organization:

- Build Awareness among the entire staff
- Find your Trauma Champions
- Revise existing policies/procedures that risk traumatization or retraumatization
- Review existing support for staff; ensure there is there sufficient resources to help identify and support staff who are struggling with secondary trauma, moral distress and compassion fatigue
- Provide training for staff to identify patients/circles of support with current and past trauma hits and what to do about it
So How Do We Know??

Potential Barriers

- Lack of energy
- Cognitive or communication impairment
- Trust and safety issues
- Desire to avoid painful memories
- Symptom management issues
- No consensus on how to assess
- Staff may not be trained or prepared to respond
Screening Tools

- Can be long
- No assessment tools have yet been validated for terminally ill patients
- Focus on past events or current symptoms, rarely both
- Perceived stigma or differential in power/status

Casting a Wider Net

- rape – sexual abuse – exposure to verbal, emotional or physical violence – death of a loved one, divorce or other significant losses – being assaulted or robbed or threatened – accidents, serious injury or motor vehicle collisions – war or acts of terrorism – serious illness of self or a loved one – medical procedures – falls – childhood illnesses or disability – surviving a natural disaster – pregnancy, birth (for mother and/or child) - surgeries or separations in infancy – growing up among drug abuse, poverty or neglect – being bullied, shamed or repeatedly criticized – racism, sexism, discrimination or homophobia – harsh parenting and/or parental mis-attunement during early attachment bonding – being imprisoned or tortured – history of drug abuse or mental illness – social, cultural and transgenerational trauma – attacks by animals – professions such as law enforcement, first responders, corrections officers, veterinary workers, hospice workers...
PTSD in the DSM-5

Re-Experiencing (one symptom)
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- Physical reactivity at trauma reminders

Avoidance (one symptom)
- Trauma-related reminders
- Trauma-related thoughts or feelings

Negative Thoughts/Feelings (two symptoms)
- Overly negative thoughts about oneself or the world
- Inability to recall key features of the trauma
- Exaggerated blame of self or others re trauma
- Negative affect
- Decreased interest in activities
- Feeling isolated
- Difficulty experiencing positive affect

Lasts 30 days; Distress or Impairment Not due to illness or Rx

The Body Goes on High Alert Searching for Trauma Reminders/Triggers

“Trauma affects the entire human organism – body, mind and brain. In PTSD the body continues to defend against a threat that belongs to the past.”

(Van der Kolk, Body Keeps the Score)

“A trigger can be any stimulus that was paired with the trauma whether we remember it or not.”

(Pease-Banitt, Trauma Tool Kit)
Reminders Can Be

- Multi-sensory (sight, sound, smell, taste, touch)
- Inner and outer physical sensations (e.g. heat, pressure, constriction)
- Memories, thoughts or images
- Emotional states (e.g. fear or helplessness)
- Situations (e.g. being crowded or immobilized)

Examples of Possible EOL Reminders

Medical care, loss of meaningful roles and routines, impaired physical function, feeling states of self or others (e.g. fear, anger, helplessness, guilt, emotional numbing), cognitive impairment, ruptures in personal boundaries, falls, relocation, loss of home, institutionalization, hospitalization, immobility, illness-related symptoms (e.g. pain, shortness of breath, racing heartbeat, GI distress, physical weakness, difficulty swallowing/choking), blood and other body fluids, loud noises, medication effects (e.g. sleepiness, loss of alertness, need for delivery through injection or suppository), smells, nightmares, direct personal care (e.g. being touched, dressed/undressed, toileting), being “stuck” in bed, perceived differentials in power (e.g. between patient and professional staff), dehumanizing situations/contexts associated with illness and/or medical care, violent television shows (including news reports), being in the dark, being naked in front of others, strangers looking over you as you lay in bed, physical examination, troubling thoughts and beliefs (e.g. “I’m alone”; “I’m not safe”; “I’m going to die”; “I can’t escape”; “I’m a burden on others”), seasonal changes and times of year associated with painful events, difficult conversations (e.g. about hospice care, treatment planning, disease progression, funeral arrangements, needing help with personal care), life review process, fears associated with death, loss, separation, impaired communication or inability to make needs known, loss of independence, increased dependency, loss of privacy, a sense of being under threat, loss of meaning and/or control, being treated or talked to “like a child,” impairments in visual or auditory acuity...
Considering a Landscape

On approach to Memphis my window frames
fields of rice, a flooded patchwork of angles
& curls lit by the pre-dawn light–
irrigation ditches & canals, east-flowing connections
to the big Mississippi, meandering its way to the Gulf.
The passenger next to me is stowing his computer.
He’s forty or so. I say, These rice farms look just like
the Mekong River Delta, & he says, Like what?

& I say, You know, those damn rice paddies in Vietnam.
We pause our descent about 5,000 feet above ground,
a flight level considered safe from small arms fire & I swear,
I hear rotor slaps & feel rotor wash against my face.

I’m strapped in the door of a Huey again –
trembling & sweating & cold. I grab an airsick bag.
C’mon man, he says, It’s thirty years since that war.
You should be over it by now.

(Feet of the Messenger, H.C. Palmer)

Fight – Flight – Freeze

- Physiological (e.g. elevated respiration, increase or
decrease in heart rate, pupil dilation, pale skin, dry mouth)
- Behavioral (e.g. impulses suggestive of flight or
defense, reactive patterns e.g. clenching muscles,
tics, etc.)
- Cognitive (e.g. increased or decreased alertness and
focus, zoning out, dissociation)
- Emotional (sudden intense reactions, e.g. anger or
fear, panic, shutting down, withdrawal, numbing)

TRICKY!
**Life Review - Proceed with Caution**

“Although effective when it promotes greater integration, self-acceptance, and positive growth, life review can also increase despair and hopelessness.”

(Glick, Cook, Moye and Kaiser, 2018)

“When key memories are trauma-related, the normal process of life review can lead to intense anxiety, sadness, guilt, or anger.”

(Feldman and Periyakoil, 2006)

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**Sample Questions**

- Have you ever been in a situation in which you were afraid you were going to die?
- Have you ever experienced something that made you feel less safe in the world or that changed you in a way that has made your life more difficult?
- Have you had any experiences in your life that have made it hard to trust/feel happy/express your needs/connect with others)?
- What was the most difficult loss you have had to face?
**Strengths and Resilience: Sample Questions**

- Can you tell me about a difficult situation where you learned something important about yourself or that changed you in a positive way?
- What would you say is your greatest strength? What would others say is your greatest strength? How did you acquire this strength?
- What got you through that experience? Where did you pull from? What’s going to help you deal with these (current illness-related) challenges?
- “Did that experience, painful as it was, deepen you in any way? Did it affect your appreciation for (friends, loved ones, inner-strength, God, life, etc.)? Did it enhance your (wisdom, perspective, compassion, empathy, capacity for expressing love or dealing with adversity, etc.)?

**Potential Comorbidities**

- Depression
- Anxiety
- ETOH and/or substance abuse
- Elevated suicide risk
- Poor adherence to medical plan
- Poor social support
- Moral and/or spiritual pain
- Wound of having been betrayed
- May be correlated with physical complications such as hypertension; cardiovascular, metabolic, musculoskeletal and autoimmune diseases; even Alzheimer’s disease
- STS in family members
So What Can We Do??

Awareness
Understanding
Safety
Compassion
Strengths-based Approach
Avoid Negative Labels
Education
Self-care and Self Awareness
Build Trauma-informed Organizations
Feldman’s Psychosocial Palliative Care Model

- Stage 1: Trust and relationship building, environmental modification, palliate immediate discomfort and optimize social support.

- Stage 2: Psycho-education, enhancement of coping and self-regulation skills.

- Stage 3: When prior stages fail to stabilize, and when patient has capacity and gives consent, focus directly on treatment and processing of traumatic material.

Models of Psychotherapy - Proceed with Caution

Traditional PTSD Therapies
- typically require multiple sessions over the course of weeks or months.
- may result in a short term increase in distressing symptoms.
- require explicit informed consent.
- may be in conflict with overall end of life goals and comfort.
- assume the traumatizing event is in the past which may not be true when the patient has a terminal illness.
- have not been studied with patients at the end of life.
Adapting Models of Counseling

Charting New Territory

Thank You!

Questions?
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Primary References/Citations

- Ganzel, B. L. (advance access publication December 6, 2016). Trauma-Informed hospice and palliative care. The Gerontologist, 00, 00, 1-11. doi:10.1093/geront/gnw146
Further References/Citations

