Trauma Informed End-of-Life Care

NCHPP Bereavement Professional Chat: August 1, 2018

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NCHPP: What is it?

- NCHPP is a collaborative of 15 discipline specific professional sections advancing end-of-life care within their disciplines.

- NCHPP's on-line resources, forums and networking will help you grow professionally, find new solutions, contribute to the field, and elevate the national profile of your program.

My.NHPCO

- Professional communities
- Discussion Posts
- Monthly Chats
- Library entries
- Blog

Please contact us…

- if you have questions about membership
- if you have topics you would like us to discuss
- if you would like to become a section committee member
- stay connected at the Bereavement Professional's MyNHPCO Community

Session Objectives

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 patients with underlying post traumatic stress and what to do about it.
4. Identify improved patient outcomes when incorporating trauma informed care in your organization.
5. Describe ways trauma informed care in your organization will decrease compassion fatigue and improve retention in your staff.


Create a Safe Place


Myth -
“Not relevant to hospice & palliative care”
… except at the VA

FOR EXAMPLE: Sexual Assault (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/ 2017 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)

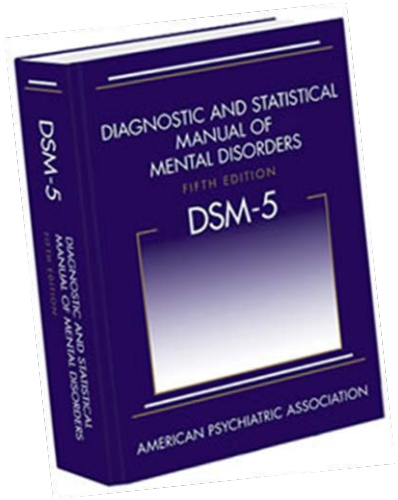
Psychological Trauma: DSM-5

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
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- Emotional distress @ trauma reminders
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Avoidance (one symptom)
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Trauma-Related Arousal/Reactivity (two symptoms)
- Risky or destructive behavior
- Hypervigilance/Heightened startle
- Difficulty concentrating
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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

TRICKY

Psychological Trauma

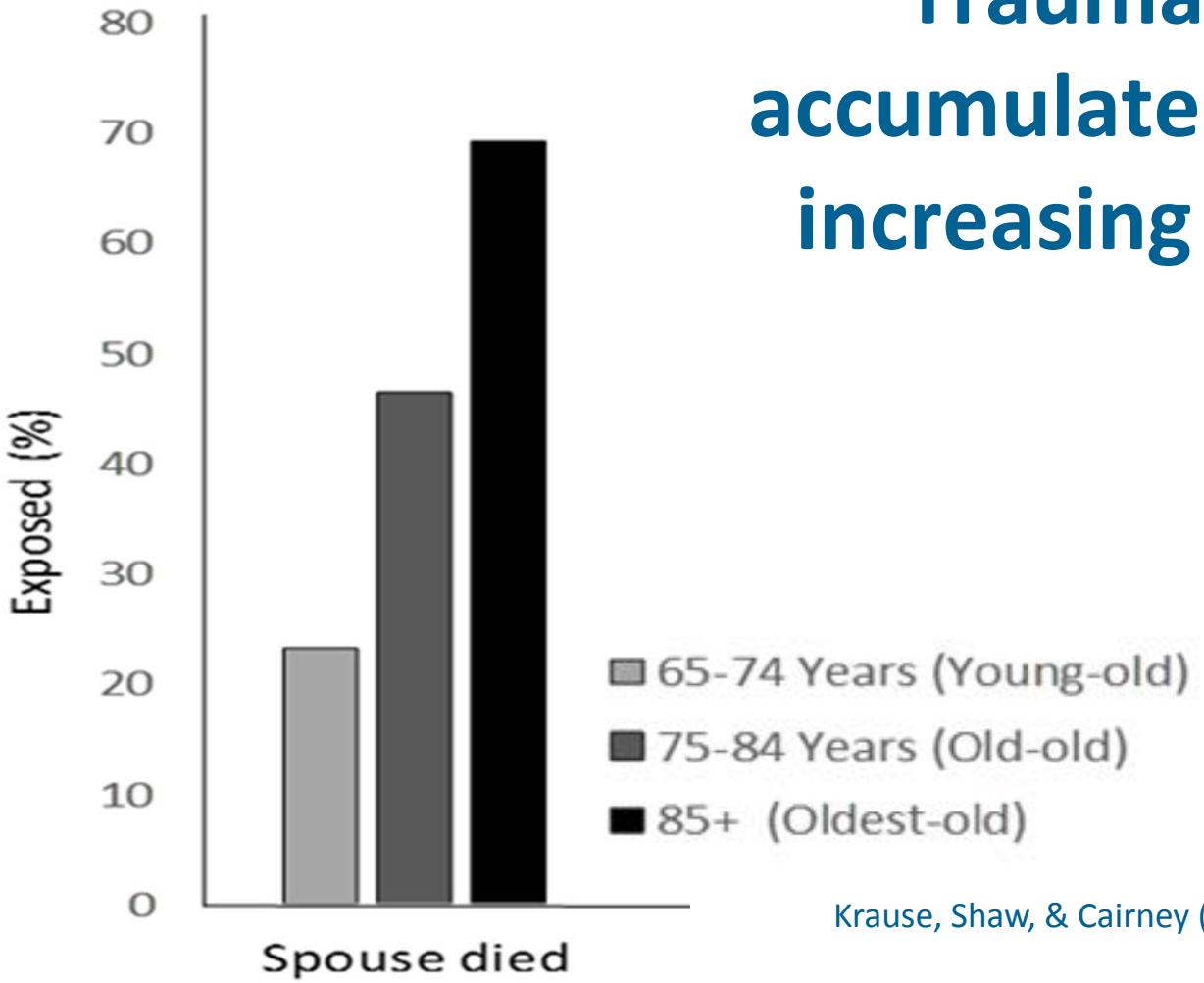
IS COMMON

- **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***

Age Range	Any Trauma
65-69 years	59.72 %
70-74 years	64.77 %
75+ years	75.51%

National Comorbidity Survey (N = 5,877)
national, representative epidemiological survey of U.S.
Kessler et al. (1995) *Archives of General Psychiatry*
Pietrzak et al. (2012). *Am. J. Geriatric Med*.

Traumas accumulate with increasing age



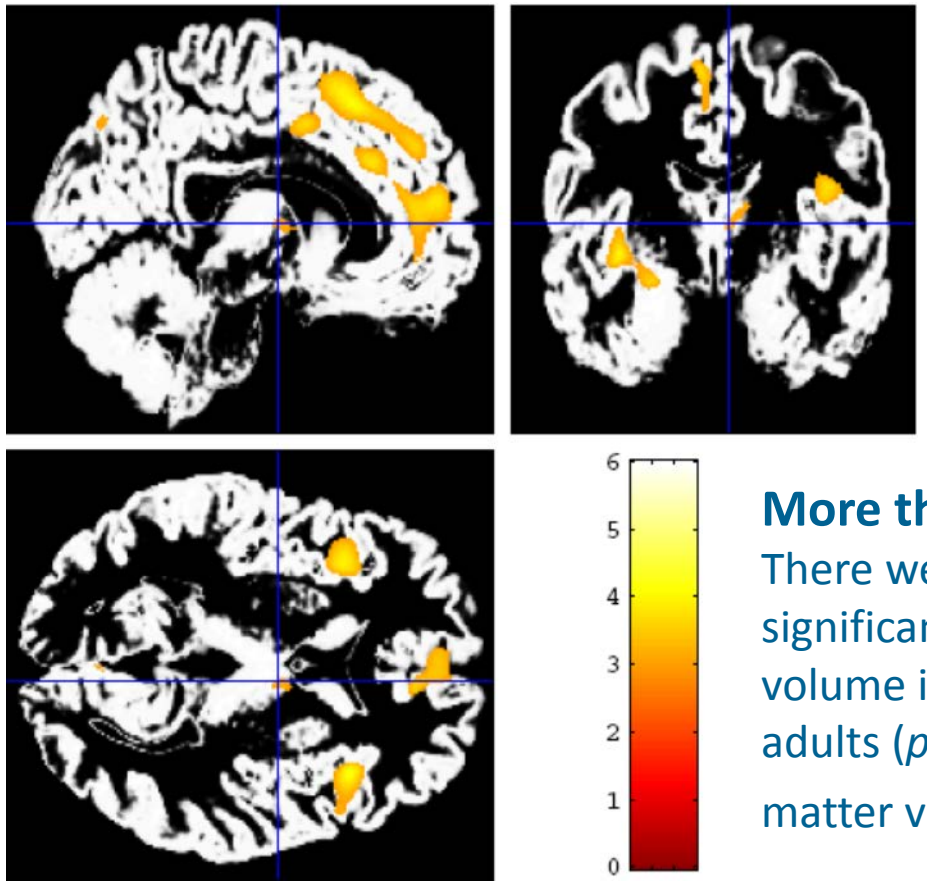
Krause, Shaw, & Cairney (2004). *Psych & Aging.*

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 …)**
  - **Increases symptoms of PTSD & future vulnerability** Ganzel, Morris, & Wethington (2010) *Psych Review*

Differences in grey matter volume

Whole-brain ANOVA (Comparison > 9/11)



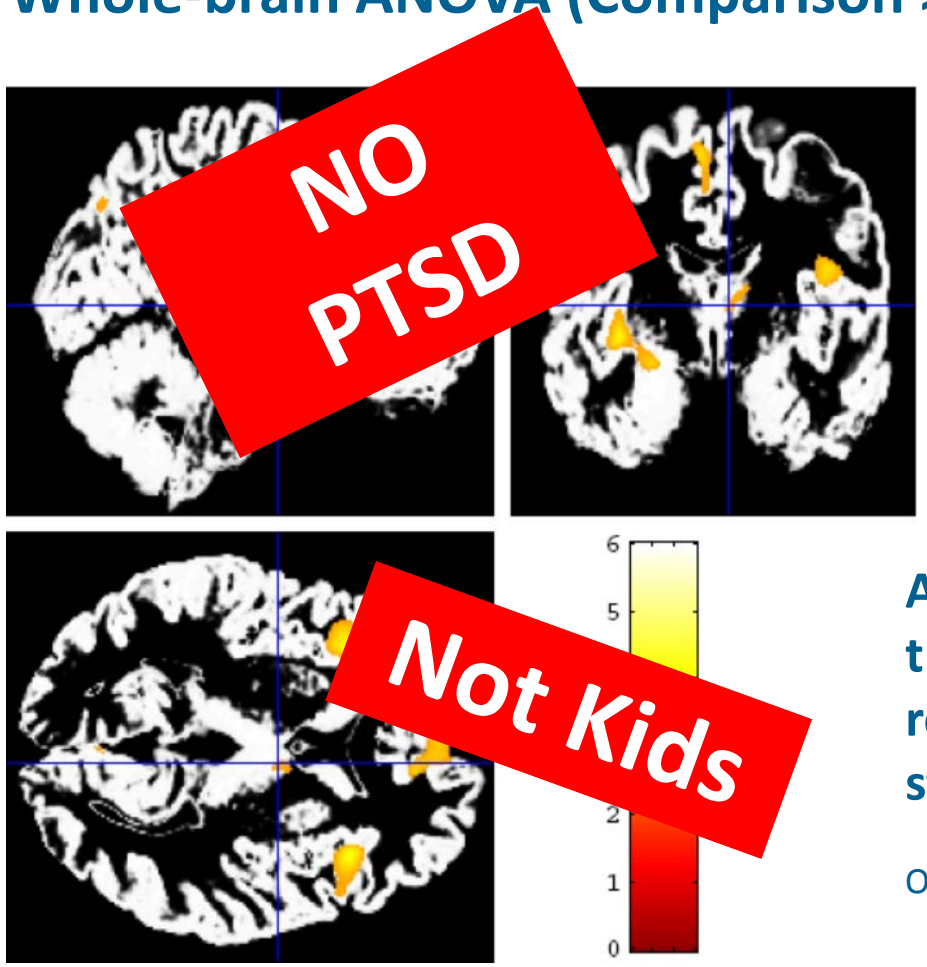
- **Anterior Cingulate**
- **Medial PFC**
- **Insula**
- **Amygdala**
- **Anterior HC**

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)

Differences in grey matter volume

Whole-brain ANOVA (Comparison > 9/11)



- Anterior Cingulate
- Medial PFC
- Insula
- Amygdala
- Anterior HC

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

Ochsner et al. (2004) Phan et al. (2002)

Sources of Trauma

Being Old

Accrual, Losses...Life Review

Reactivation of old trauma memories

- ***Can <u>reactivate</u> prior PTSD***
  - *++ in the context of ill health*
- ***Can result in <u>new</u> PTSD***
  - ***even if the initial trauma didn't***

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

LOSS - Late Onset Stress Symptomatology

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 Symptomology 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)

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

So How Do We Know??

Potential Barriers

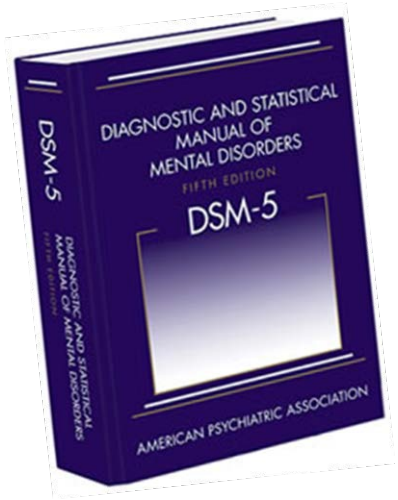
- Lack of energy
- Cognitive or communication impairment
- Trust and safety issues
- Desire to avoid painful memories
- Symptom management issues
- No consensus on how to assess
- Staff may not be trained or prepared to respond

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

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 – series 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*…



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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)

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)

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?

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

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)

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

The Culture of Trauma Informed EOL Care

Impact on the Patient/Circle of Support

- Identifies patents 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)

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 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

What's Next?

- ❖National Council of Hospice & Palliative Professionals [NCHPP] Section Chats over the remainder of 2018 and into 2019
- ❖Presentation at the NHPCO IDC in New Orleans in November
- ❖NCHPP collaboration to develop curricula and blueprints

- ✓ *Not one size fits all*
- ✓ *Tiered or step models*
- ✓ *Continuum of increasing TIC at EOL components*
- ✓ *Trauma Champion(s) –*
  - ❖ *Create a ListServe to support EOL TIC discussion & collaboration*

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Questions?

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