Questions and Answers About Trauma-Informed End-of-Life Care

Developed by NHPCO's Work Group

Several national entities promote varying definitions of trauma. NHPCO has adopted the definition provided by the Substance Abuse and Mental Health Services Administration (www.samhsa.gov) as its depth and breadth are most relevant to the hospice and palliative care field.

> Individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being. (Substance Abuse and Mental Health Services Administration; www.samhsa.gov)

As a result of a traumatic experience, some people may develop conditions meeting specific diagnostic criteria, such as major depression, generalized anxiety disorder, or post-traumatic stress disorder. However, even those that do not meet official diagnostic criteria may have lasting negative effects and can be considered to have had a traumatic experience.

1. Why and how is trauma-informed end-of-life care important to the art and science of hospice and palliative care?

The data is clear that as we age, experience health challenges, and receive medical care, our chances of experiencing some form of trauma increase significantly—to some 75% by the time we are 75 years old. Additionally, exposure to potential traumatic events is estimated to be as high as 80% in the United States (Kilpatrick et al., 2013) and 70% worldwide (Benjet, et al., 2016). Our failure to realize the impact of trauma, recognize its signs and symptoms, respond appropriately, and resist-re-traumatization (SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach; pages 9 - 10) of patients/families* at the end of life and staff who care for them comes at a tremendous cost for all involved:

- Patients/families experience unnecessary suffering, poor outcomes, and low satisfaction (National Council for Behavioral Health; SAMHSA);
- Staff face risks to their physical, emotional, social, and spiritual health (Center for Healthcare Strategies; SAMHSA); and
- Organizations contend with unnecessary consumption of resources, decreased staff morale and productivity and may experience costly service failures (National Council for Behavioral Health).

Our informed preparation for and response to underlying trauma, including the development of policies and procedures as well as protocols, is necessary if we are to evolve to the next level of clinical and organizational excellence in hospice and palliative care.

* Patients/Families: NHPCO recognizes that individual organizations may use varying terminology to refer to the people they serve. Patients/families is used in NHPCO publications and is consistent with regulatory and accreditation language in the field. Since the inception of hospice care in the U.S., the definition of "family" has been very broad and is inclusive to all people identified as important and influential in a patient's life.

2. How is "trauma-informed end-of-life care" different from the care currently being provided?

A person/family-centered approach is fundamental to the provision of hospice and palliative care; it requires that we see patients and families as equal partners in care with a focus on goals and interventions that align with their desires and values. Trauma-informed end-of- life care is about so much more.

As we take a "universal precautions" approach to trauma-informed end-of-life care, we will be more cognizant of truly *seeing* the people in front of us and *hearing* the stories they carry within them that impact their experience of care.

Our ability to be increasingly aware of and sensitive to the ways in which even simple actions such as turning on a ceiling fan, taking a blood pressure reading, or discussing routine paperwork may trigger a negative reaction will require us to slow down and be much more intentional about the way we engage in every interaction.

Without this deepened awareness and sensitivity, we place ourselves and those we serve at risk. With it, we will overcome judgments and defenses about our behaviors and interactions that may "trigger" re-traumatization for patients and families in our care. How easily re-traumatization can occur will begin to make much more sense once we understand the prevalence, potential sources, and impact of trauma both in the immediate and long term. The result will be our ability to instinctively refrain from asking "What's wrong with you?!" but, instead ask, "What happened to you?" With this shift in our perspective, we do not excuse difficult or questionable behavior, but we also do not pathologize it.

We are essentially describing a cultural shift in the hospice and palliative care field and within ourselves. This is a shift away from disrespect and lack of understanding and toward respect and curiosity that will serve patients/families and ourselves far better.

While the treatment of trauma, PTSD, and related concerns are generally not within the scope of practice in hospice and palliative care, we retain the responsibility to respond to distress and pain (regardless of its source) in patients and families receiving care, to provide appropriate symptom management and to practice in a manner that is respectful, compassionate and that maintains the dignity of those in our care.

3. What characteristics and skills are needed to practice in a "trauma-informed" manner?

In addition to one's discipline-specific/professional training and education about hospice and palliative care, the following skills have been identified by NHPCO's Trauma-Informed End-of-Life Care Work Group (2019) as being vital.

- Cultural humility: A philosophy, approach, and comfort with not knowing and openness to learning; an "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]" (Hook, 2013). Cultural humility is a life-long process of learning and self-reflection that facilitates understanding of differences and similarities between one's own beliefs, values, and goals with those of others, in this case patients and their families who receive care (Schuessler et al., 2012). It means that we approach all with unconditional positive regard.

  For additional information/education about cultural humility:
  www.chcs.org/cultural-humility-key-element-trauma-informed-care
  www.nctsn.org/trauma-informed-care/culture-and-trauma
  www.ncbi.nlm.nih.gov/pmc/articles/PMC3834043

- Understanding of trauma and its symptoms (https://store.samhsa.gov/product/TIP-57-Trauma-Informed-Care-in-Behavioral-Health-Services/SMA14-4816) and the ability to explain them accurately and in appropriate language to those receiving care in a manner that helps them understand trauma symptoms and their genesis.
- Knowledge of trauma-informed care and more specifically, trauma-informed end-of-life care (https://store.samhsa.gov/system/files/sma14-4884.pdf)
- Characteristics of compassion, kindness, respect, sensitivity, non-judgment, patience
- Skills/abilities of presence, attunement, active listening, a "beginner's mind" (https://jackkornfield.com/beginners-mind/), normalizing, pacing, focusing on strengths, ability to respect boundaries, actively resisting re-traumatization.
- Keen self-awareness and acknowledgement of one's own limits and triggers, knowledge of how to maintain one's own grounded-ness, how to avoid psychological distancing, how to self- regulate and manage one's own reactions and responses.
- Repertoire of concrete tools to provide palliation of trauma symptoms in patients/families (e.g., breathwork and visualization exercises, mindfulness approaches, body-awareness and grounding exercises, cognitive approaches, expressive therapies, such as music and art, and other tools to be used by interdisciplinary team members).

It is important to acknowledge additional strategies that can be used to address trauma symptoms by those who have been properly trained to use them, such as trauma-focused CBT (cognitive behavioral therapy) and EMDR (eye movement desensitization and reprocessing) among others. In some organizations, these more advanced modalities are practiced by licensed social workers, pastoral counselors, or bereavement professionals as well as other staff. In all interventions, the focus of these approaches is the palliation of trauma symptoms in an effort to meet identified plan of care goals.

4. How can hospice and palliative care professionals discern if patients, family or caregivers have had traumatic experiences?

NHPCO's Trauma-Informed End-of-Life Care Work Group suggests that professionals be attuned to the presentation of symptoms of traumatic stress when caring for patients and their families. Given the statistics, it is more common than not for those in your care to have had experiences of trauma.

Thus, approaching all with a "universal precautions" mindset with respect to trauma (just as one would take precautions with all bodily fluids) is recommended. Be attentive to potential symptoms of traumatic stress when they are observed and use your best clinical skills to invite exploration as appropriate and within the scope of your professional practice or licensure. Use the trauma-informed end-of-life care framework that is being discussed here as a guide. Key to addressing symptoms of traumatic stress is doing everything possible to avoid re-traumatizing an individual.

Presently, there is not a validated screening or assessment instrument or tool for traumatic stress at the end-of-life. Thus, attunement to potential symptoms of traumatic stress in an informal assessment is the best method to discern if they are present. When they are, end-of-life care professionals need to work within the interdisciplinary team to further explore and adapt the plan of care as necessary to address them.

5. When reactivation of trauma occurs near the end of life, how is it experienced?

It is helpful for professionals to consider this question from the holistic perspective that undergirds quality care at the end of life; reactivation can be manifested in a myriad of ways. Just as each patient and family member is unique and brings to the end of life his/her own unique experiences, reactivation of traumatic experiences is also wholly unique. Reactivation of trauma can be experienced and expressed physically, socially, emotionally, cognitively and/or spiritually. Reactivation may become apparent through one's relationships, interactions, and behaviors, for example. Thus, focusing one's perspectives on the holistic person and keenly listening, observing, and evaluating *what* is occurring *and how* it is occurring may help you attune to the reactivation of traumatic experiences. Attend to nuances that present themselves; they may provide opportunities for you to gently explore and to learn more about a person's past experiences and current reactions and symptoms.

The following table of trauma reactions and symptoms may be helpful; professionals will note many of them as common also to the end-of-life experience. It is not all inclusive but can provide an idea of the many ways that trauma symptoms can present themselves.

Trauma Reactions and Symptoms	
Immediate Emotional Reactions Numbness and detachment Anxiety or severe fear Guilt (including survivor guilt) Exhilaration as a result of surviving Anger Sadness Helplessness Feeling unreal; depersonalization (e.g., feeling as if you are watching yourself) Disorientation Feeling out of control Denial Constriction of feelings Feeling overwhelmed	**Delayed Emotional Reactions** Irritability and/or hostility Depression Mood swings, instability Anxiety (e.g., phobia, generalized anxiety) Fear of trauma recurrence Grief reactions Shame Feelings of fragility and/or vulnerability Emotional detachment from anything that requires emotional reactions (e.g., significant and/or family relationships, conversations about self, discussion of traumatic events or reactions to them)
Immediate Physical Reactions Nausea and/or gastrointestinal distress Sweating or shivering Faintness Muscle tremors or uncontrollable shaking Elevated heartbeat, respiration, and blood pressure Extreme fatigue or exhaustion Greater startle responses Depersonalization	**Delayed Physical Reactions** Sleep disturbances, nightmares Somatization (e.g., increased focus on and worry about body aches and pains) Appetite and digestive changes Lowered resistance to colds and infection Persistent fatigue Elevated cortisol levels Hyperarousal Long-term health effects including heart, liver, autoimmune, and chronic obstructive pulmonary disease

Immediate Cognitive Reactions Difficulty concentrating Rumination or racing thoughts (e.g., replaying the traumatic event over and over again) Distortion of time and space (e.g., traumatic event may be perceived as if it was happening in slow motion, or a few seconds can be perceived as minutes) Memory problems (e.g., not being able to recall important aspects of the trauma) Strong identification with victims	**Delayed Cognitive Reactions** Intrusive memories or flashbacks Reactivation of previous traumatic events Self-blame Preoccupation with event Difficulty making decisions Magical thinking: belief that certain behaviors, including avoidant behavior, will protect against future trauma Belief that feelings or memories are dangerous Generalization of triggers (e.g., a person who experiences a home invasion during the daytime may avoid being alone during the day) Suicidal thinking
Immediate Behavioral Reactions Startled reaction Restlessness Sleep and appetite disturbances Difficulty expressing oneself Argumentative behavior Increased use of alcohol, drugs, and tobacco Withdrawal and apathy Avoidant behaviors	**Delayed Behavioral Reactions** Avoidance of event reminders Social relationship disturbances Decreased activity level Engagement in high-risk behaviors Increased use of alcohol and drugs Withdrawal
Immediate Existential Reactions Intense use of prayer Restoration of faith in the goodness of others (e.g., receiving help from others) Loss of self-efficacy Despair about humanity, particularly if the event was intentional Immediate disruption of life assumptions (e.g., fairness, safety, goodness, predictability of life)	**Delayed Existential Reactions** Questioning (e.g., “Why me?”) Increased cynicism, disillusionment Increased self-confidence (e.g., “If I can survive this, I can survive anything”) Loss of purpose Renewed faith Hopelessness Reestablishing priorities Redefining meaning and importance of life Reworking life’s assumptions to accommodate the trauma (e.g., taking a self-defense class to reestablish a sense of safety)
Sources: Briere & Scott, 2006b; Foa, Stein, & McFarlane, 2006; Pietrzak, Goldstein, Southwick, & Grant, 2011.	

Substance Abuse and Mental Health Services Administration. Trauma-Informed Care in Behavioral Health Services. Treatment Improvement Protocol (TIP) Series 57. HHS Publication No. (SMA) 13-4801.Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014.

6. How do/can professionals re-traumatize patients/families and what does it mean to "actively resist re-traumatization?"

NHPCO's Work Group recommends that each person in your care be treated with a "universal precautions" approach; an approach that is well understood in medical care. From this perspective, consider that it is probable that a person in your care has had a traumatic experience that may be reactivated during end-of-life care (patients as well as family members). Professionals are advised to be attuned, as mentioned above, by keenly listening, observing, and evaluating *what* is occurring and *how* it is occurring, which may provide clues to past experiences and their impact on care at the end of life.

When professionals learn of specific past traumatic experiences, they can adapt or adjust their interventions to minimize the potential for re-activation.

For example:

- A gentleman was a POW during his military service where he experienced great fear and dread during his imprisonment. During his hospice care, he learned that he could experience diarrhea as a medication side effect which led to similar feelings of fear and dread. His anticipated reaction to bouts of diarrhea triggered, in his mind, his previous POW experience of fear and dread. The awareness of his experience and reaction was very important information for the hospice interdisciplinary team who, when the medication was implemented, worked with the patient and his wife to develop a plan for managing it (and his reactions/responses) in advance.
- A woman with a history of sexual abuse was very uncomfortable being touched, especially when the hospice aide provided personal care and bathing. The aide was able to minimize the patient's discomfort by telling her, in advance, each part of her body that she was going to touch next and getting her permission to do so.
- A woman who was a Holocaust survivor was told that "we are going to clean up now" vs. "let's go to the shower" by the person providing care. Knowing that showers or baths meant certain death at concentration camps, she was able to use a compassionate and trauma-informed approach.

Anything can reactivate a trauma; sights, sounds, the weather, the clothes you wear, the look on your face. There are reactivations of trauma that we cannot know and that we cannot control. Given this reality, professionals are encouraged to remain acutely aware and open to what is being presented to you and how it is being presented. Adopt a "beginner's mind" as discussed above and approach everyone with curiosity and openness. As always, remember the adage "start where they are." Use a person-centered approach and craft your interactions and interventions around each specific person and his/her unique experience. It can be helpful to ask yourself these questions:

- How is the volume, tone, and timbre of my voice? The pace of my words?
- How do my facial expressions engender confidence (or fear)?
- Where should I position myself in space (taking into consideration the dynamics of gender, race, power, etc.)
- What can I do that will increase trust?
- What can I do to communicate and demonstrate safety?
- How can I avoid creating discomfort during this visit/interaction?
- How can I provide opportunities for this person to exercise choice? To grant permission?

7. If a hospice and palliative care professional becomes aware of their own traumatic reactions, what should they do?

As sobering as the statistics about the prevalence of trauma for patients/families we serve may be, it is equally stunning to recognize that the same numbers apply to us and our teams.

Staff may experience “vicarious trauma” (Vicarious Trauma Fact Sheet; Understanding & Addressing Vicarious Trauma) as they witness or learn of patient/family trauma experiences and/or symptoms, become aware of their own traumatic reactions to challenging care situations or workplace dynamics, or experience re-activation of their own previous trauma.

Self-awareness is the key. Professionals’ insight into their own histories will help them better understand their own reactions and, along with proper training, be better prepared to navigate moments of countertransference. (Attending to Countertransference; Transference vs. Countertransference) In addition, self-understanding of the “why” of one’s reaction and knowing what to do with it are paramount.

Our personal reactions are natural and to be expected. Anticipating, recognizing, and acknowledging them is also expected for us as we practice the highest level of professional and clinical competence. With greater understanding, communication, and respectful partnership between and among individuals, teams and organizations, risks for everyone involved will decrease as the provision of excellence in service and outcomes improve.

Professionals are encouraged to access resources to help them address and manage their own traumatic reactions, such as an informed clinical supervisor or a personal or professional therapeutic professional. Key to the helpfulness of these resources is understanding the impact of trauma and how to help manage it, of course, professionals may need to advocate for their own help.

Organizational policies and procedures that keep leaders and teams mindful of the risks and vigilant about providing proper support is also critical for prevention, management, and intervention. A “trauma-informed” organization (Trauma Informed Care; Trauma Informed Organizations; Key Ingredients) will ensure staff resources.

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