Title

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Journal

Journal of Palliative Medicine, 29(8)

ISSN

1096-6218

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Publication Date

2026-08-01

DOI

10.1177/10966218251366151

Peer reviewed

HHS Public Access

Author manuscript

J Palliat Med. Author manuscript; available in PMC 2025 December 11.

Published in final edited form as:

J Palliat Med. 2026 August ; 29(8): 1145–1152. doi:10.1177/10966218251366151.

Top Ten Tips Palliative Care Clinicians Should Know About Trauma-Informed Care

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Author Disclosure Statement

No competing financial interests exist.

Abstract

Trauma is a personal stress response to experiences perceived as harmful or life-threatening, and has ongoing impacts on illness and health. Exposure to trauma is increasingly prevalent, and the risk of medical trauma or retraumatization is heightened for people living with serious illness. Trauma not only impacts health outcomes, but can also interfere with decision-making and worsen symptom burden at the end of life. Thus, it is critical that palliative care clinicians in all professions be skilled at providing high-quality trauma-informed care (TIC). TIC seeks to provide more holistic and equitable care through better understanding of how a person's life situation impacts behavior, reactions, behavior, responses, or relationships. A clinician using a trauma-informed lens asks, "What has happened to this person?" instead of, "What is wrong with this person?" A "universal precautions" approach is recommended, encouraging broad acknowledgment of possible trauma and recognition of signs of trauma responses, to better understand triggers for medical retraumatization among patients, caregivers, and even us as clinicians. TIC provides a framework that guides clinicians to acknowledge the widespread experience and consequences of trauma, recognize the symptoms of traumatic stress, mitigate mistrust and disempowerment, and advocate for culture change in health care systems to reduce the risk of further health care-based traumatization.

Keywords

patient agency; palliative care; psychosocial issues; serious illness; trauma-informed care; traumatic stress

Introduction

Traumatic stress is associated with increased overall distress and symptom burden during serious illness and end-of-life care.[1,2] About 70% of adults in the United States report experiencing at least one potentially traumatic event during their lifetime,[3] and among people with mental health diagnoses or substance use disorders, trauma is an "almost universal experience."[4] National palliative care (PC) guidelines[5] call for clinician assessment of trauma symptoms as well as clinician competency in creating a trauma-informed care (TIC) plan when appropriate. Yet, these guidelines do not specify how to integrate TIC into clinical practice.

The Substance Abuse and Mental Health Services Administration describes TIC as policies, procedures, and practices to protect the vulnerabilities of those who have experienced trauma by creating a supportive environment and practices that prevent retraumatization.[6] Notably, TIC is distinct from specialized psychotherapy for trauma. Patients who are interested in long-term treatment for traumatic stress should be referred accordingly.[7] Instead, TIC encourages clinicians to practice the "four R's" of care: (1) realizing the long-term impact of trauma on health and relationships; (2) recognizing signs of traumatic stress; and (3) responding to trauma in ways that (4) resist retraumatization.[8] Table 1 summarizes the 10 key tips for incorporating TIC into clinical care of patients with serious illness or at end-of-life.

Tip #1: Definitions of What Experiences Constitute Trauma are Personal and Depend on Individual Backgrounds and Interpretations. Trauma can be Historical or Ongoing and can Stem from Myriad Sources, such as Medical, Individual, Childhood, Interpersonal, Intergenerational, Political, and Societal Adversity

Trauma can be an acute, unexpected event like a car accident or a chronic experience, such as abuse, war or armed conflict, natural disasters or public health emergencies, structural racism, or protracted medical care. Exposure to multiple, prolonged traumas over a lifespan, known as cumulative trauma, increases the likelihood of post-traumatic stress disorder (PTSD).[9] Traumatic stress may also be experienced as a result of generational trauma, i.e., trauma that is epigenetically passed down through generations before us.[10]

Trauma is subjective, influenced by one's unique history and coping style, and dependent on the perceived suffering of the person experiencing the event. While two people may experience a similar event, only one may experience it as traumatic. Separately, vicarious or secondary trauma may be experienced by individuals who did not personally experience a traumatic event. For instance, traumatic responses may manifest for individuals who were exposed to the traumatic events of others, including PC clinicians providing service to individuals experiencing distressing/life-threatening illness and injury (also see Tip #9).

Because many patients with serious illness and their families have experienced trauma at some point in their lives, PC clinicians must be aware of how serious illness, hospitalization, and interactions with health care may trigger trauma responses. PC clinicians may be viewed as representatives of an untrustworthy system for patients and families who have previously experienced harm when engaging with systems. Coping strategies that patients and families have developed in response to personal or communal trauma, such as remaining silent about trauma, may impact their willingness to communicate about this experience with clinicians.[11,12] Provision of TIC supports more health equity by mitigating the biopsychosocial sequelae and interrupting the cycle of cumulative stress within health care.

Tip #2: Trauma Accumulates Over a Lifetime. Increased Trauma Exposure is Correlated with a Greater Number of Health Conditions, Risky Health Behaviors, Earlier Mortality, and Higher Symptom Burden in the Last Year of Life

The Adverse Childhood Experiences (ACEs) study was one of the first to demonstrate a dose-response effect between adversity in childhood (e.g., abuse, neglect, living in households where there is substance use or incarceration) and ill health in adulthood. For example, people who experience four or more categories of ACEs have two times the rate of lung and liver disease, three times the rate of depression and alcohol use disorder, 11 times the rate of opioid use via injection, and 14 times the rate of attempted suicide. People with six or more ACEs died nearly 20 years earlier on average than those without ACEs. Likewise, as health effects accrue and become amplified at or near the end of life, so may the need for potentially traumatic medical interventions that increase the likelihood of health care re-traumatization.[13,14]

As clinicians caring for people with serious health conditions and their caregivers, it is crucial that PC clinicians are aware of the high likelihood that people may have experienced

trauma at earlier points in their lifetime. In one national survey, one-third of patients in the last year of life reported three or more potentially traumatic events over their lifetime. Moreover, patients in the same study[1] with more lifetime trauma were found to have significantly higher burdens of pain, fatigue, depression, and social isolation, with lower quality of life compared to those with lower trauma scores.

Tip #3: Trauma Symptoms Manifest Across Multiple Domains, Including the Physical, Psychosocial, and Existential-Spiritual Realms; Symptoms May Manifest from a Primary Trauma or Resurface with Health Care Retraumatization

Traumatic stress symptoms shown in Table 2 are typically characterized within four categories:

- Intrusion or re-experiencing (of memories or physiological sensations);
- Avoidance of reminders of trauma, including thoughts, places, people, etc.;
- Negative alterations in mood and cognition (e.g., ongoing shame, fear, negative feelingsabout the world, detachment);
- Hyperarousal (e.g., a hyper-reactive fight, flight, or freeze response to perceived threats).[15]

Trauma symptom phenotypes may vary across individuals and contexts.[16,17] The bio-psycho-social-spiritual impacts of traumatic stress are well documented, and the symptom manifestations in each of these domains can have effects across the lifespan.[18] Recognizing signs or symptoms of traumatic stress is the first step for PC clinicians to be attuned to a potential traumatic response and employ a compassionate TIC approach.

TIC guides clinicians to understand the patient's behaviors in relationship to past traumatic experiences and responses. Without this lens, clinicians may inaccurately misinterpret a patient's behavior and/or personality, resulting in the mislabeling of patients as "difficult" or "non-compliant," which in turn affects communication. Instead, TIC encourages clinicians to consider that patients' expressions of distress may reflect strategies that they have used to survive trauma(s) in the past.[19]

Tip #4: Trauma Among Patients with Serious Illness is Common. A History of Trauma Increases a Patient's Risk of Experiencing new Medical Trauma or of Re-Experiencing Prior Traumas, Especially when Engaged in Complex Decision-Making, Coping with High Symptom Burden, or Anticipating the End of Life

Serious illness exposes patients and caregivers to many potential forms of medical trauma. Nearly two-thirds of adults with serious illness report experiencing traumatic stress.[20] While high rates of PTSD have been documented in patients and caregivers following an admission to the intensive care unit,[21] everyday experiences of medical care can also result in traumatic stress.[22,23] Health experiences that may elicit traumatic stress include intense medicalization, receipt of frightening news, loss of autonomy and control, or invasive imaging or procedures. As such, serious illness is not a singular trauma, but made up of complex events unfolding over time that can recur and culminate in a final threat of death.[24,25]

Routine medical care can also trigger prior trauma, whether medical-related or not. Generally, medical environments—rife with frightening sights, sounds and touch—heighten stress responses in patients and caregivers.[6,15,26] Likewise, complex decision-making, conversations involving reviews of illness courses or receiving devastating news, and intense meetings with multiple care teams can potentially trigger patients and families as they revisit old and ongoing sources of threats to safety.

Dying itself can be an especially vulnerable time, especially if a death is traumatizing to experience or witness due to severe and refractory symptoms (e.g., pain, breathlessness, or agitation) or catastrophic events such as hemorrhage or respiratory failure. Even supportive interventions at the end of life, such as receiving intimate touch during difficult conversations, life review, and legacy work, may unwittingly retraumatize patients if they trigger memories of previously unprocessed trauma.[11,27]

Tip #5: TIC Takes a "Universal Precautions" Approach to Care for all Patients and Caregivers, Particularly Those with a Sensitivity to Previous Trauma. While this Approach Allows for Inquiry About Potential Histories of Trauma that may Manifest as Stress Responses Affecting Current Care, it Does NOT Require Formal Screening About the Details of a Patient's Trauma History nor a Specific Mental Health Diagnosis

Given the high prevalence of trauma among those with serious illness and the acknowledgment that all individuals—patients, caregivers or family members, and even members of the clinical team—may be affected by past trauma, experts advocate for a "universal precautions" approach to practicing TIC.[28] Clinicians do not need to know the details of these traumatic experiences to apply universal precautions in anticipation that most people have experienced some degree of trauma in their lifetime and are at risk of experiencing high levels of stress given the context in which we meet them. Even when a history of trauma is known, clinicians may have limited knowledge of the specifics of past traumatic events, and it may be harmful to explore a patient's trauma history in depth without proper training.

At the same time, clinicians are encouraged to learn whether prior experiences may be impacting a patient's response to present illness. PC clinicians can use open-ended questions such as, "Have you ever experienced anything that makes seeing a health care clinician difficult or scary for you?" or, "As people live with serious illness, they sometimes experience reminders of prior scary events. Has this happened to you?"[29] When engaging in this inquiry, it is imperative for PC clinicians to provide empathic responses that acknowledge, normalize, and validate the experiences of patients while remaining open and nonjudgmental.

Tip #6: Key TIC Principles Include Promoting Physical, Psychological, and Interpersonal Safety; Building Trustworthiness and Transparency; and Awareness of the Influence of Cultural, Historical, and Gender Factors. Practices to Promote these Principles Should be Shared with Other Staff and Clinicians

TIC seeks to mitigate risk for trauma and re-traumatization through six key principles (continued in Tip 7). Three of these key principles include (1) safety, (2) trustworthiness

and transparency, and (3) awareness of cultural, historical, and gender influences. Safety includes a physical, psychological, and interpersonal sense of security, allowing for a reduced fear of threats to one's well-being. Trustworthiness and transparency are cultivated through interventions, treatments, and organizational operations conducted with honesty. PC clinicians can foster environmental and interpersonal safety through the following practices shown in Table 3.[28]

Clinical care that fosters safety includes seeking permission before entering a patient's hospital room, providing bedside care, or initiating touch, and respecting patient boundaries regarding time spent having difficult conversations and number of clinicians in the room. PC clinicians delivering TIC can build trust and transparency through clear communication, consistency, and transparency in actions and decisions, such as being honest about known delays in imaging or procedures.

Understanding the influence of cultural, historical, and gender factors on trauma is crucial to promote culturally responsive care and acknowledge how these factors may impact an individual's experience of trauma, ensuring that care is tailored to their specific needs. This can include acknowledging if a clinician misspeaks or misinterprets an aspect of the patient's care and offering a plan to rectify the action, such as "I apologize for the word I just used, I know that was upsetting, and going forward I will avoid using it," or using patients' chosen names and preferred pronouns.

Tip #7: TIC Empowers Patients, Maximizes Patient Agency, and Encourages Collaboration and the Development of Internal and Community Resources Where Possible

Other key principles of TIC include (4) empowerment, voice, and choice; (5) collaboration and mutuality; and (6) peer support. TIC aims to empower patients and caregivers by giving choices, offering control where possible, recognizing strengths, and respecting expertise.[31,32] For example, clinicians should offer choices when possible (e.g., attire preferences, timing of updates, clustering of medications and care, and communication preferences related to receiving serious news or health updates).[33] Choices may also include offering patients the option of deciding which symptom to talk about first during a PC visit or asking how many clinicians a patient prefers having in the room at one time. Patient autonomy can be respected by creating opportunity for agency and bodily control (e.g., seeking permission prior to use of touch during an encounter).

To empower and strengthen an individual's coping skills, PC interprofessional teams can identify and offer methods patients prefer to use when triggered (e.g., grounding, mindfulness exercises, deep breathing, going for a walk). Several resource guides offer TIC communication training for adult[32] and pediatric[34] populations. Collaboration and mutuality involve leveling power differences between patients, caregivers, and clinicians during health care decision-making so that care plans align with patient and caregiver preferences. This partnership centers around "doing with" rather than "doing to."

Lastly, TIC recognizes the value of peer support and encourages individuals to connect with others who have similar experiences to build a sense of community and belonging. PC teams

can support this by offering mutual support resources and supporting the presence of a patient's advocates and trusted peers in medical visits or decision-making.

Tip #8: TIC is Aligned with PC Tenets, such as Patient-Centeredness, Mutuality; Uplifting Sources of Strength and Comfort, and Attention to the Psychosocial, Spiritual, and Existential Aspects of Illness and suffering

Cicely Saunders' recognized the holistic relation between illness and suffering in PC with her description of total pain,[35] which emphasizes understanding and alleviating all forms of suffering.[36] TIC similarly encourages clinicians to approach care by seeking to understand, "What has happened to you?" rather than the traditional medical model of, "What is wrong with you?" Thus, TIC centers the whole person, asking us to broaden our frame from a narrow view of a patient with a set of problems to be fixed toward a complex human with various life, cultural, or historical experiences, which may shape their encounter with traumatic stress and impact their current health care interactions. TIC is inherently strengths-based, celebrating the personal and community strengths demonstrated when surviving adversity.

In both TIC and PC, cultivating partnerships is key to promoting collaboration and mutuality that promote healing. For example, PC centers a patient's values, goals, and views of life to rebalance a patient's authority in defining what matters most in their care. Similarly, understanding power dynamics between the patient and clinician and attempting to redistribute that power through shared decision-making so that patients and clinicians may collaborate on a care plan is fundamental to both PC and TIC. In this way, TIC represents an attuned sensitivity to, and stewardship of, past or present traumas through an active, compassionate presence.[37]

Tip #9: TIC Includes Caring for Ourselves as Clinicians, our Health Care Colleagues, and our Teams. TIC Encourages Self-Compassion and Awareness of Personal Traumas that can be Reactivated and Vicarious Trauma that can be Experienced through Caring for Others

The health care system and care environment can induce or exacerbate trauma responses for patients and staff alike, especially when caring for people with serious illness or at the end of life. For PC clinicians, health care industry infrastructure imposes demanding expectations on training and practice across professions and care settings.[38] Care delivery itself can remind a clinician of their own history of trauma, which can then influence their practice and sense of well-being.[39] Furthermore, increasing demands on clinicians with limited time or support may lead to feelings of burnout, compassion fatigue,[40] and moral distress.[41] Without education on how to appropriately identify and respond to patients' traumatic stress in clinical encounters, PC clinicians may also experience low self-efficacy that can further impact stress responses.

When intentionally integrated into reflective practice and self-care, TIC can enhance clinicians' self-awareness of how one's own experiences and responses to stress are a result of their unique bio-psycho-social-spiritual history. This awareness is an important step towards identifying and accessing resources that support safety, well-being, and

adaptability.[42,43] Awareness, compassion, and self-reflection, combined with proper training, can thus equip PC clinicians to better understand their own reactions and navigate potential moments of countertransference.

Tip #10: TIC Must be Implemented at Multiple Levels, from Clinical Practices that Reduce the Risk of Medical Traumatization to Organizational Health care Systems that Foster Nondiscriminatory, Equitable, and Anti-Racist Environments for both Patients and Staff

Systemic and structural inequities that perpetuate trauma, such as racism, remain pervasive within medicine. These injustices contribute to ongoing disparities that affect both patients and clinicians. People of color and individuals from lower socioeconomic backgrounds living with serious illness face inequitable access to specialty PC in both inpatient and outpatient settings and are less likely to benefit from PC consultations when compared to White patients.[44–47] Patients from these populations are often found to receive less aggressive pain management, lower quality end-of-life care, and care with less concordance to personal values.[44,48–50] These systemic disparities reinforce historical disenfranchisement from the health care system based on race, gender, socioeconomic status, immigration status, and mental health, among other factors.[51] Thus, the risk of medical re-traumatization for patients who are already more likely to have been exposed to potential trauma at baseline is compounded.

TIC encourages PC clinicians and leaders to critically examine how structural racism, underlying policies, unconscious bias, and health care culture exacerbate the risk for further medical trauma to patients and staff alike, and to advocate for changes that mitigate and correct this potential harm.[51–54] PC leaders can build trauma-informed workplaces by rectifying divisive policies, revising hiring initiatives, designing clinical environments, and elevating wellness to be more trauma-informed through cultivating diverse, collaborative, and equitable work environments for PC clinicians from all backgrounds.[55]

Building a trauma-informed workplace requires strong PC leadership to shift organizational culture. PC leaders serve as advocates and role models who communicate about the importance of becoming trauma-informed, engaging patients in organizational planning, investing in trauma-informed training for clinical and non-clinical staff,[6] and creating a physically and psychologically safe workplace.

Conclusion

Integrating TIC into serious illness and end-of-life care is imperative given the pervasiveness of trauma exposure and its significant lasting consequences on mental, physical, and spiritual health. TIC principles align with the patient-centered, holistic practices fundamental to hospice and PC and are key when caring for seriously ill patients at risk of medical trauma and retraumatization. PC clinicians are uniquely suited to integrate trauma-informed principles that provide more responsive and responsible care for patients and their caregivers and to promote more durable culture change across health care systems through role modeling and advocacy.

Funding Information

No funding was received for this article.

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TABLE 1.

Top Ten Tips Palliative Care Clinicians Should Know about Trauma-Informed Care

Tips
1. Definitions of what experiences constitute trauma are personal and depend on individual backgrounds and interpretations. Trauma can be historical or ongoing, and can stem from myriad sources, such as medical, individual, childhood, interpersonal, intergenerational, political, and societal adversity.
2. Trauma accumulates over a lifetime. Increased trauma exposure is correlated with a greater number of health conditions, risky health behaviors, earlier mortality, and higher symptom burden in the last year of life.
3. Trauma symptoms manifest across multiple domains, including the physical, psychosocial, and existential-spiritual realms; symptoms may manifest from a primary trauma or resurface with healthcare re-traumatization.
4. Trauma among patients with serious illness is common. A history of trauma increases a patient's risk to experience new medical trauma or to re-experience prior traumas, especially when engaged in complex decision making, coping with high symptom burden, or anticipating the end of life.
5. Trauma-informed care takes a "universal precautions" approach to care for all patients and caregivers, particularly those with a sensitivity to previous trauma. While this approach allows for inquiry about potential histories of trauma that may manifest as stress responses affecting current care, it does NOT require formal screening about the details of a patient's trauma history nor a specific mental health diagnosis.
6. Key trauma-informed care principles include promoting physical, psychological, and interpersonal safety; building trustworthiness and transparency; and awareness of the influence of cultural, historical, and gender factors. Practices to promote these principles should be shared with other staff and clinicians.
7. Trauma-informed care empowers patients, maximizes patient agency, and encourages collaboration and the development of internal and community resources where possible.
8. Trauma-informed care is aligned with palliative care tenets, such as patient-centeredness; mutuality; uplifting sources of strength and comfort; and attention to the psychosocial, spiritual, and existential aspects of illness and suffering.
9. Trauma-informed care includes caring for ourselves as clinicians, our healthcare colleagues, and our teams. TIC encourages self-compassion and awareness of personal traumas that can be reactivated and vicarious trauma that can be experienced through caring for others.
10. Trauma-informed care must be implemented at multiple levels, from clinical practices that reduce risk of medical traumatization to organizational healthcare systems that foster non-discriminatory, equitable, and anti-racist environments for both patients and staff.

TABLE 2.

SYMPTOM MANIFESTATIONS OF TRAUMATIC STRESS IN DIFFERENT DOMAINS AND ACROSS A LIFESPAN[8]

Domain	Manifestation
Physical-cognitive	- Sleep disturbances (nightmares or insomnia) - Changes in appetite or eating patterns - Exaggerated startle response - Fatigue and headaches - Reactions like sweating, rapid breathing, fast heart rate - Memory problems (e.g., not being able to recall certain details of trauma) or difficulty concentrating - Intrusive thoughts or flashbacks of the traumatic event, rumination - Somatization (increased focus on and worry about the body, aches, pains) - Delayed responses may include: Magical thinking (e.g., belief that certain behaviors like avoidance will protect against future trauma), generalization of triggers (e.g., avoiding cars after a car accident), suicidal thinking
Psycho-social-behavioral	- Social withdrawal or isolation - Avoidance of triggers or situations related to the trauma - Engaging in high-risk behavior or substance use as coping - Hypervigilance - Anxiety, agitation - Sadness - Confusion - Blunted affect - Dissociation - Numbness or avoidance of emotions - Depression - Shame - Emotional detachment from anything that involves emotional reactions (e.g., conversations about self, family relationships, etc.)
Spiritual/ existential	- Intense use of prayer - Trauma often engenders a crisis of faith or core, life-organizing assumptions that can lead to questioning life and views about self, the future, and/ or the world, for example: - Views about self: “I have no purpose,” “I am incompetent,” “I feel damaged” - Views about the future: “Things will never be the same,” “What’s the point?,” “It’s all hopeless” - Views about the world: “People cannot be trusted” “Life is unpredictable,” “The world is a dangerous place.” - People who attempt to share their interpretation and meaning of the event can feel misunderstood and sometimes alienated. (e.g., Does the event represent retribution for past deeds committed by someone or themselves? What is the meaning attached to survival? Is there a greater purpose not yet revealed? - Cynicism, disillusionment - Delayed reactions could include: reestablishing priorities, re-working life’s priorities to account for trauma (e.g., taking a self-defense class), hopelessness

TABLE 3.

CLINICAL PRACTICES TO PROMOTE SAFETY AND TRUSTWORTHINESS[30]

Clinical practices
Seek permission before entering a patient's hospital room, providing bedside care, or initiating touch.
Avoid personalizing language in a physical exam, e.g., "To evaluate your mucositis and mouth pain, I will need to look in the back of the mouth," rather than, "Open your mouth for me."
Provide time and space for patients to ventilate emotions by looking for cues that can signal anxiety or activation (e.g., long verbal pauses, sighs, and restlessness). For instance, "I know talking with others about this [topic/issue] can sometimes be overwhelming or cause feelings of anxiety. If you'd like, we can pause here and take a break to just breathe."
Consider an established "safety" word(s) or gesture (e.g., moving the bedside table, turning on the TV) to end the conversation if the patient feels unsafe.
If patients feel "trapped," hang mirrors to allow visibility of the door and all parts of the room. Remain in their line of vision.
Respect patient boundaries regarding time spent having difficult conversations and number of clinicians in the room.
If a patient is having a flashback, do not touch them. Rather, call the patient's name in a calm voice and explain where they are and what you're doing, e.g., "I am X, we are in your room at Y Hospital. You are safe here." Repeat this until the patient becomes oriented.
If a clinician misspeaks or misinterprets an aspect of the patient's care, acknowledge it, and offer a plan to rectify.